

LIFE AFTER STROKE

‘A life I like’ and ‘A life to live’

Deborah Ruth Neal

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ABSTRACT

This doctoral thesis describes, critically evaluates and reflects on the development and evaluation of an innovative approach to supporting individuals after a stroke. This approach consists of; a once-weekly, twelve week, stroke self-management programme consisting of interactive information provision, rehabilitation and exercise in an environment of peer and caregiver support called 'ASPIRE' – an acronym for **A**cute stroke, **S**elf-management support, secondary **P**revention, **I**nformation, **R**ehabilitation and **E**xercise. The development of the ASPIRE programme was influenced by interviews with those involved in the ASPIRE programme and the process and results of a primary research evaluation using mixed methods. The aim of this two phase evaluation was to 1) identify participants' views as to the outcomes of attending the ASPIRE programme, using a grounded theory approach and 2) identify whether those outcomes could be assessed using currently existing standardised validated tools.

Three key themes were identified; *A life I like* – the confidence to do the everyday activities important to a person after a stroke; *Changing hearts and minds* – the confidence, knowledge and health behaviour change to reduce vascular risk after stroke and *In the same boat* – the benefits of peer support for stroke survivors and caregivers. These themes were used to select relevant standardised validated tools; the Stroke Knowledge Test (SKT), Stroke Self Efficacy Questionnaire (SSEQ), Cerebrovascular Attitudes and Beliefs Scale (CABS-R), Hospital Anxiety and Depression Scale (HADS) and Caregiver Strain Index (CSI). Statistically significant gains were identified in the SKT and HADS – depression score. The tools were useful and sensitive to change; however, the SSEQ had a ceiling effect with this cohort and the CABS-R was found difficult to use.

Although existing outcome tools may not adequately measure new multi-factorial post-stroke interventions such as the ASPIRE programme, the unique contributions of this doctoral thesis to the body of knowledge are that;

- An enabling culture, that includes peer support for stroke survivors and caregivers, helps individuals to move forward after stroke.
- Support for self-generated goal planning, based on a 'life-thread' approach, may improve outcomes from stroke survivors' perspectives.
- Supporting individuals to develop the confidence, knowledge and health behaviours to reduce vascular risk can be an integral and complementary part of rehabilitation after stroke. A multi-factorial programme to enable life after stroke should therefore include both rehabilitation "A life I like" and secondary prevention "A life to live".
- Individually tailored exercise programmes to support rehabilitation and secondary prevention can be used with groups of stroke survivors with a wide range of deficits.

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Chapter 1: Introduction

1.1 Introduction

The focus of this professional doctorate is facilitating the development of self-management skills through an innovative complex intervention, the ‘ASPIRE’ programme, in order to support individuals to move forward to life after stroke in terms of rehabilitation “a life I like” and secondary prevention “a life to live”.

1.2 Introduction to this thesis

This introductory chapter sets the context for this thesis, which results from a professional doctorate programme, with requirements to complete in any order; **(1) a practice development project** and **(2) primary research** both supported by **(3) a literature review** plus **(4) a reflexive synthesis** that demonstrates the integration of the other components. For this author, this was an iterative rather than a sequential process, with the practice development and primary research components supporting and informing each other. To support the doctoral process, the author kept a practice development diary ‘praclog’ and a diary to capture the research and overall doctoral process ‘doclog’. These diaries were used to support the reflections captured in the reflexive synthesis.

Although the overall doctoral process was iterative and interwoven, for simplicity the structure of this thesis mirrors a more traditional doctorate with literature review, followed by methodology, results and discussion. These first four chapters focus on the literature review, practice development and primary research project and so are written in the third person. The final two chapters are reflective and so are written in the first person. In the fifth chapter, the author reflects on how the research and practice development impact on practice. In the final chapter, the author reflects on her personal journey, completing a professional doctorate alongside working full time as a consultant physiotherapist for a National Health Service (NHS) Trust and a University. The six chapters of this thesis are supported by a number of appendices as outlined in the index and cross referenced in the text.

1.3 Background - Stroke and transient ischaemic attack

A stroke is described by the World Health Organisation (WHO) as damage to the brain tissue, due to loss of oxygen and nutrients, following an interruption to the blood supply, due to either a burst blood vessel or one that is blocked by a clot (WHO, 2012). Transient ischaemic attack (TIA) has been defined as:

“a transient episode of neurological dysfunction caused by focal brain, spinal cord or retinal ischaemia without acute infarction” (Easton et al, 2009).

TIA, often referred to as ‘mini’ or temporary stroke, is a serious condition despite its brevity, as those who have had TIA are at high risk of stroke within the subsequent 90 days (Wu et al, 2007), with one population based study finding about 12% dying within a year of TIA (Kleindorfer et al, 2005). Overall, about 20% of TIA survivors subsequently have a stroke (Thacker et al, 2010); and the risk of vascular events remains high for at least ten years after TIA or stroke (van Wijk, 2005).

Stroke is one of the three highest causes of death in the UK (Morse, 2010) and the largest cause of complex disability in the United Kingdom (Adamson et al, 2004). Worldwide stroke leads to more than 5 million deaths annually; many in developing nations where hypertension often remains undiagnosed and untreated (WHO, 2012). The global stroke epidemic is likely to worsen in future years due to the increase in obesity levels, with 12% of the global population now classified as obese or morbidly obese (WHO, 2012); and due to the ageing population. The Framingham heart study, a 30 year longitudinal study of 5184 men and women, demonstrated an age related increasing risk of stroke associated with atrial fibrillation (Wolf et al, 1987). Of those who have stroke, 60% will die or be dependent by the time of discharge from hospital, even with the best stroke care (WHO, 2012). On the whole, women will have worse outcomes after stroke than men, as women tend to be older at the time of first stroke (Appelros et al, 2010). In addition, there is a higher prevalence of atrial fibrillation amongst women which leads to a higher proportion of the more severe cardio-embolic strokes (Seshadri et al, 2006).

Death from stroke has decreased over recent years in many Western countries; this may in part be due to the success of primary prevention measures, implemented to reduce cardiovascular mortality as a whole, leading to lower levels of smoking and better diagnosis and control of blood pressure (Berger et al, 2006; Ray et al, 2010). In addition, since the publication of the first National Sentinel Audit of stroke (Rudd et al, 1999), mortality and morbidity in acute stroke has decreased significantly due to the wider implementation of the evidence base around management of Transient Ischaemic Attacks (TIA), thrombolysis, organised stroke unit care and early supported discharge (Henssge et al, 2011; Rudd et al, 2004). In addition to regular national audits of stroke, changes in practice have been supported by the publication of a series of clinical guidelines (Intercollegiate Stroke Working Party, 2000; 2004; 2008; 2012; NICE, 2008) and the National Stroke Strategy (Department of Health, 2007).

Although incidence of first ever stroke is decreasing worldwide, due to earlier detection and treatment of vascular disease, the ageing population and ineffective secondary prevention could impact this reduction. Stroke is often regarded as an acute illness; however, stroke survivors are at far greater risk of a further stroke in the first year after stroke than the general population, and also of other subsequent or related illness of both vascular and non-vascular origin (Mogensen et al, 2013). Stroke is therefore now recognised as a long term condition, (Broomhead et al, 2012; Winchcombe, 2012) with significant health and social care costs (Morse, 2010). For those who survive stroke, there is significant variance in outlook in terms of physical and psychosocial consequences and general health and wellbeing (Chau et al, 2009; De Weerd et al, 2011; Kwakkel et al, 2006; Teasdale & Engberg, 2005).

Some of this variance may be due to the impact of time since stroke on recovery (Kwakkel et al, 2006). Some variance may be due to the inclusion and exclusion criteria used for the study populations, such as the exclusion of those under 65 years of age (De Weerd et al, 2011), even though age has been shown to have little effect on functional outcomes (Bagg et al, 2002). Other variance is due to the amount and intensity of rehabilitation people receive (Morse, 2010), despite established evidence that 'more is better' (Bode et al, 2004; Kwakkel et al, 2004).

Those after stroke often have limited rehabilitation input (Esmonde et al, 1997; Bernhardt et al, 2004), and that which they do have, has been shown to rarely reach intensities that will maintain or increase their levels of cardiovascular fitness (Mackay-Lyons & Makrides, 2002).

As a consequence, many people after a stroke tend to have significantly lower levels of physical activity compared with the general population of older adults (Ashe et al, 2009; Michael et al, 2005). In addition many of those with chronic hemiparetic stroke have to work to exhaustion just to carry out many everyday activities (Ivey et al, 2005). This is due to the impaired central movement control system due to the stroke and also due to peripheral changes; these include overall atrophy of muscles, a shift in muscle phenotype from predominantly type 1, slow twitch, fatigue resistant fibres to type 2, fast twitch fibres (Ivey et al, 2005) and also reductions in peripheral blood flow and arterial diameter (Billinger, 2010). This is likely to contribute to the significant proportion of stroke survivors who experience a further decrease in functional ability later after stroke; for instance De Weerd et al (2011) found the functional abilities of 31% of their study population had deteriorated at 1 year post-stroke.

Even in those with stable physical and neurological function, social and psychological functioning can deteriorate in the year following stroke (Suenkeler et al, 2002). A significantly higher prevalence of depression and anxiety has been found than in a comparable non-stroke population (De Weerd et al, 2011; Hackett et al, 2005). Fatigue after stroke, both physical and mental, may predict a decline in mobility function and also impacts on a number of aspects of life; including daily function, dependency levels, sexual activity, ability to work full time, social and leisure activities and life satisfaction (Lerdal et al, 2009).

Data, from a long-term follow up study of people with first-ever stroke, found that by ten years after the index stroke event, 79% had died; with the major causes of death being the effects of the initial stroke and cardiovascular disease (Hardie et al, 2003). Anderson et al (2004), investigating very long term outcomes after stroke, found that only 7% were still alive after 21 years; of these 12% lived in

institutional care and 19% required help with everyday activities. These data clearly show the need to support people to optimise their recovery from the stroke.

It is recognised that there is an association between the quality and quantity of social relationships after stroke and the risk of cardiovascular disease (House et al, 1988) and of mortality (Holt-Lunstad et al, 2015). It is thought that increased social support acts as a buffer to help reduce the impact of stress or other negative mood states. It is known that a significant proportion of stroke survivors will suffer from depression (Ayerbe et al, 2013; Bartoli et al, 2013). Those that are depressed are at increased risk of; social isolation, poor quality of life, reduced or deteriorating functional ability (Ayerbe et al, 2012) and mortality in the medium term, 2- 5 years after stroke (Bartoli et al, 2013). It is also known that greater self-efficacy and perceived social support can reduce the risk of post-stroke depression (Lewin et al, 2013). It is less clear what strategies are best used to increase perceived social support; a recent review by Salter et al (2010) identified only one intervention aimed at improving social support; that intervention was a 3 month, social-worker led, care coordination intervention (Claiborne, 2006).

More recently, Kamiya et al (2010) have investigated which components of social relationships impact most on cardiovascular risk. Direct measures of four risk factors (hypertension, obesity and the presence of two inflammatory markers within blood samples) were compared in relation to objective measures of social support such as social ties (number of close friends and relatives); social participation; and subjective measures such as perceived emotional support. The study involved; two waves of face to face interviews, a nurse visit, a blood test and a large sample size (10,770) representative of the English population. Although most measures were dichotomised, which could reduce the accuracy of the findings, Kamiya et al (2010) found that social participation consistently predicted lower risk of all four risk factors and that there was a reduced risk of hypertension for those married or cohabiting. This study indicates that an intervention, which leads to increased social participation, is likely to reduce cardiovascular risks; however, the impact of the stroke on an individual, their caregivers and families should also be considered.

For stroke survivors, their caregivers and families, the early days after discharge from hospital present challenges to relationships, identity and integration into the community. The transition phase immediately after discharge is particularly stressful (Rittman et al, 2007). An interview study of 90 informal caregivers of stroke survivors, one year after stroke, found that most felt inadequately prepared for the role and were not assessed for their capabilities to undertake it (Smith et al, 2004). In addition a significant proportion of stroke caregivers are depressed (Berg et al, 2005).

The age, health, race and gender of the caregiver has been shown to impact on their emotional well-being and their experience of caring (Bugge et al, 1999; Jessup et al, 2015). Family caregiver stress has been shown to negatively impact on outcomes for stroke survivor and carer (Grant et al, 2013) and is often linked to long term institutionalisation of stroke survivors (Bakas et al, 2014). Stroke survivor variables and caregiver variables have both been shown to impact the caregiver. Bugge et al (1999) found that caregiver's well-being was affected by the functional abilities of the stroke survivor. A recent prospective study of 183 stroke survivors and their partners demonstrated a link between; high burden, anxiety and depression in caregivers; depression and low mood in stroke survivors; plus age, relationship satisfaction, self-efficacy, pro-active coping and social support in the caregivers themselves (Kruithof et al, 2016). Appropriate support for stroke survivors and caregivers, that reduces caregiver burden, should improve short and long term outcomes for caregivers and stroke survivors.

Evidence on how best to support stroke survivors and caregivers, at the point of transition immediately after discharge from hospital, is contradictory. A large-scale, cluster, randomised, controlled trial found no evidence that training for caregivers, in the form of a structured skills based programme, reduced caregiver burden (Forster, Young et al, 2012). There is some evidence that caregivers groups can benefit participants; by providing emotional support, information and an ability to compare situations with others (Larkin, 2007).

For those who have already had a stroke or a TIA, there is an increased risk of recurrent stroke (Sacco et al, 2006). There is also a risk of death from coronary artery disease, with studies showing an increased risk of Myocardial Infarction (MI) in the first year following ischaemic stroke (Feng et al, 2010). The increased risk of heart disease is due to common risk factors and disease processes such as atherosclerosis (Adams et al, 2003). Overall, there are widely variable reports of the incidence and prevalence of recurrent stroke (Feng et al, 2010; Hardie et al, 2004). Hardie et al (2004) report the risk of recurrent stroke to be six times greater than in an age and gender matched population, with a 4% annual risk of recurrent stroke after the first year. Despite improvements in stroke care over recent years, Feng et al (2010) report a risk of recurrent stroke of 8% in the first year, then between 2.9% and 4% in each of the subsequent three years. Feng et al (2010) report the cumulative risk of recurrent stroke, MI or vascular death to be 24.7% over the first year and 41.3% over the first four years. The lack of improvement in risks in the six years between the publications of Hardie et al (2004) and Feng et al (2010) may reflect differences in the populations studied, or may be attributable to limited improvement in implementation of secondary prevention strategies after stroke.

Recurrent stroke causes additional morbidity and mortality (Talelli & Greenwood, 2008), and with relatively higher rates of death and institutionalisation than first stroke (Hankey et al, 2002), causes an even higher human and economic burden both individually and system-wide (Spieler et al, 2003). Although risk of death is particularly high (22%) in the first 30 days after a first ever stroke, for those having a recurrent stroke, 30 day case fatality is even higher at 41% (Hardie et al, 2004). For those after TIA or non-disabling stroke, the risk of stroke or death could be much higher (Coull et al, 2004); from 10% in the low risk group up to 31% in the high-risk group (Kernan et al, 2000). There is also a greater likelihood of mental health issues, such as depression and reduced self-esteem, after recurrent than after initial stroke (Fung et al, 2006). These risks, plus financial and human costs, provide powerful justification for effective strategies to be developed, which reduce the risk of stroke or other vascular events after stroke or TIA, and which are implemented as soon as possible after stroke and continued over time.

There are numerous risk factors for stroke and recurrent stroke, some of which are non-modifiable, including male gender, family history or increasing age. Many of those with stroke or TIA also have modifiable vascular risk factors including hypertension, atrial fibrillation, obesity, hyperlipidaemia, diabetes, physical inactivity and smoking (Furie et al, 2011). Strategies shown to reduce recurrent stroke risk are; the use of appropriate surgical techniques such as carotid endarterectomy or angioplasty and stents; the use of relevant medication such as statins, antihypertensives and blood thinners; and making changes in lifestyle factors (Furie et al, 2011). Some lifestyle changes; avoiding smoking (Hurley, 2005; Iso et al, 2005), increasing physical activity (WHO, 2012), maintaining a healthy body weight (Douketis & Sharma, 2005); eating a healthy diet rich in fruit and vegetables (He et al, 2006) and low in saturated fat and salt (Ding & Mozaffarian, 2006); inevitably impact on more than one risk factor.

Secondary prevention guidelines recommend combining appropriate medication for the treatment of vascular risk factors such as hypertension with the modification of behavioural risk factors such as physical inactivity (Kernan et al, 2014); however, adherence to medication and behaviour modifications needed to reduce lifestyle risk factors are known to be sub-optimal (Alvarez-Sabin et al, 2009; Brewer et al, 2015). There is evidence in other long term conditions, that medication adherence and modification of lifestyle risk factors, can be improved by supporting a self-management strategy (Newman et al, 2004, Taylor et al 2014). A recent meta-review of current self-management support provision for stroke survivors found current practice focused on; daily activities, quality of life and information provision, rather than secondary prevention (Taylor et al, 2014).

1.4 Background - Self-management

Self-management is the ability to live an active and meaningful life with a long term condition (Lorig & Holman, 2003). Self-management is underpinned by a person-centred values base (Ahmad et al, 2014) and sits within a biopsychosocial model; one that considers the biological, psychological and social domains of health (Tomkins & Collins, 2006). The processes of self-management include; goal setting, self-monitoring, decision making, planning, engaging in and evaluating health behaviours in order to manage long term conditions or risk

factors (Ryan & Sawin, 2009). The terms self-management and self-care are often used interchangeably. Self-management has been defined as:

“The individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a long term disorder” (Tomkins & Collins, 2006, p6).

In contrast, self-care is defined as

“the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.” (Tomkins & Collins, 2006, p6).

Self-care is therefore a broader term, with a focus on primary prevention, and is something that everyone can do, irrespective of whether or not they have a long term condition. It includes activities such as taking regular exercise, eating a healthy diet and attending for dental check-ups. Self-management, for those with one or more long term conditions, is focused on that or those conditions, so may include: taking relevant medication, following a specific diet, using equipment to support function or using pacing strategies to reduce fatigue. Although many self-care activities, such as healthy eating, also support those with a long term condition to self-manage, since the term ‘self-care’ can be used to refer to the ability to carry out basic activities of daily living, such as washing and getting dressed (Guidetti et al, 2009), the term self-management has been used throughout this thesis to avoid confusion.

Not everyone wishes, or is able, to take a self-management approach to their long term condition (Corben & Rosen, 2005). In part, this can depend on an individuals’ level of activation; their knowledge, skill and confidence to manage their own health (Hibbard et al, 2005); and also on the degree to which the person perceives their health to be an output of their own behaviour, i.e. *“beliefs about whether actions affect outcomes (locus of control)”* (Bandura, 1997, p20). These beliefs are clearly critical to self-management, as someone who believes that their own behaviour has little or no impact on their own health, is less likely to take responsibility for initiating behaviour change which may have a positive impact on their current and future health. A further factor is an individuals’ self-efficacy; the confidence a person has in their capabilities and competence to achieve a

specific action, which can influence their expectations and achievement of that outcome (Bandura, 1997).

It is known that in order for those with long term conditions to participate fully in society, and care appropriately for their own health, they may require the provision of information and advice or the development of skills which result in increased self-esteem and confidence, and changes in lifestyle or attitude (Chambers et al, 2006). It is recognised that the methods of information provision after stroke need improving, and there is a lack of consensus as to the best way and time to provide that information (Forster, Brown et al, 2012). Providing information through group discussion supports peer learning and supports those with low levels of health literacy (Stonecypher, 2009). Group based interventions may not meet the need for individualised information provision identified as crucial (Stonecypher, 2009; Sullivan et al, 2008). Support for the benefits of individualised, interactive, information provision also comes from a study that showed that an individualised, information pack (CareFile) had a positive impact on knowledge of stroke, at 3 and 6 months post stroke, though no impact on mood or satisfaction (Lowe et al, 2007). The interactive discussion with patients about the content of the CareFile happened during their inpatient stay, so took no account of the change in information required in relation to time post-stroke (Hanger et al, 1998).

Information provision and even knowledge acquisition do not always lead to change in health beliefs, or predict changes in health behaviours, sufficient to reduce risk of stroke. Sullivan et al (2009), in a study of an at-risk population, found that; belief about susceptibility to stroke was the biggest indicator of health behaviour change; health beliefs about barriers and subjective norms were predictive of behaviour change in relation to weight loss; and beliefs about benefits and self-efficacy were more likely to play an important role in health beliefs about exercise. Sullivan et al (2009) therefore recommended that, to change health behaviour in relation to exercise and stroke risk, interventions should focus on increasing knowledge about the benefits of exercise and also maximise individual's self-efficacy towards exercise.

Professionals may support people with long term conditions to self-manage through; providing information, encouraging those with long term conditions to manage and monitor their condition, and to take appropriate action when needed. This action may include seeking professional help in a proactive and timely manner and making changes to lifestyle or behaviour. Supporting self-management also includes having conversations that challenge health beliefs and providing information in a way that enables a person to use appropriate and relevant knowledge. This contrasts with 'patient education' as demonstrated powerfully in a randomised, controlled trial by Lewin et al (1995). This study found that; those on the waiting list for coronary artery bypass graft surgery, whose health beliefs were challenged, and who had received appropriate information; had a significant reduction in angina, and the need for surgery compared with those attending standard lifestyle education sessions. Types of support for self-management vary along a continuum; from teaching technical skills, to challenging health beliefs, to supporting or promoting self-efficacy. The type of input needed along that continuum will vary according to a person's level of activation (Hibbard & Gilbert, 2014).

There is evidence that, even with expert patients, the way services are currently provided, and the attitude of health professionals, may prevent the implementation of a supported self-management approach; if health professionals fail to find out what the real issues are, or make suggestions that are unachievable in an individual's circumstances (Corben & Rosen, 2005; Tomkins & Collins, 2006). As a person-centred approach, self-management support requires a paradigm shift; from the traditional, paternalistic, biomedical model of health service delivery to a biopsychosocial approach (Engel, 1977). The biopsychosocial approach encompasses all aspects of health; including biological, psychological, cognitive, social and behavioural (Tomkins & Collins, 2005). This holistic view of health and well-being is also integral to a person-centred rehabilitation process which considers physical, personal and social context and involves both goal setting and learning (Wade, 2015). A person-centred, holistic, biopsychosocial ethos was fundamental to the practice development project for this doctoral programme which includes elements of self-management support and rehabilitation.

1.5 Context for the practice development project

In 2004, a review of stroke services found that; patients' and caregivers' knowledge of stroke, and of the lifestyle changes needed to reduce the recurrent risk of stroke, was poor (Rudd et al, 2004). This was followed, in 2005, by a survey of stroke patients, carried out by the Healthcare Commission, and reported in 'Nobody told me' (Stroke Association, 2006), which found that less than half of those questioned felt they had been given information on preventing a further stroke. A subsequent poll, for the Stroke Association (Stroke Association, 2006), reinforced this finding as 57% of those polled reported that they were not given any information about healthy eating, and only two-thirds reported being given any information about physical activity levels. A series of focus groups, held for the Stroke Association, on perceptions of information provision (Carluccio et al, 2006) found marked differences in provision, between different areas of the country, so it was unclear whether these findings, reporting lack of information about secondary prevention, applied locally.

A local audit (Table 1) was therefore carried out, using identical questionnaires to those used in the national audit (Stroke Association, 2006). Questionnaires were sent out to 50 consecutive people, discharged from the hospital's acute stroke unit. There were 18 replies, a 36% response rate; 7 were male and 11 female. Respondents were aged from less than 50 (2 respondents) to over 90 (1 respondent) with 3 aged between 50 and 70 and the majority (12) aged between 71 and 90.

Despite performing well in the 2006 National Sentinel audit for stroke, the findings from this local audit (Table 1) reflected the Stroke Association's national findings; that patients had limited knowledge of stroke and secondary prevention. Reviewing the case notes of the patients involved in the audit found that, in nearly every case, it was documented that all this information had been given. Over the previous decade, stroke services had been the focus of much investment and improvement, including changes in the organisation and process of care. This had led to better outcomes; lower mortality and morbidity and lower inpatient costs, due to reductions in average lengths of stay (Rudd et al, 2004). With average lengths of stay now only a few days, these audit findings might reflect that the

stroke survivors were in shock and unable to remember secondary prevention advice given before their discharge; or that information may have been given in a way that did not help the person retain the information (Carluccio et al, 2006).

Table 1: Local audit of information provision after stroke

| Question | No | | Yes | | Partially | | Total |
|---|-----|-----|-----|-----|-----------|-----|-------|
| | (n) | (%) | (n) | (%) | (n) | (%) | |
| Were you given enough information on medications? | 12 | 67% | 6 | 33% | 0 | 0% | 18 |
| Were you given advice on prevention? | 12 | 67% | 6 | 33% | 0 | 0% | 18 |
| Were you given enough information overall? | 10 | 56% | 8 | 44% | 0 | 0% | 18 |
| Were you given information on diet / cholesterol? | 9 | 50% | 6 | 33% | 3 | 17% | 18 |
| Were you given information about exercise? | 8 | 44% | 8 | 44% | 2 | 11% | 18 |
| Were you given information about weight? | 8 | 44% | 4 | 22% | 6 | 33% | 18 |
| Were you told what type of stroke you had? | 6 | 33% | 9 | 50% | 3 | 17% | 18 |
| Were you given information on alcohol? | 5 | 28% | 4 | 22% | 9 | 50% | 18 |
| Were you given information about smoking? | 4 | 22% | 2 | 11% | 12 | 67% | 18 |
| Was your diagnosis explained? | 4 | 22% | 10 | 56% | 4 | 22% | 18 |

This lack of knowledge is not confined to the United Kingdom. A Swedish study (Sloma et al, 2010), of those with previous stroke or TIA, found that although most participants knew about general stroke risk factors such as hyperlipidaemia, hypertension and smoking, only 62% of participants reported previous stroke / TIA as a risk factor. In addition, knowledge about diabetes as a risk factor was low, even in those with diabetes, which is of particular concern as stroke recurrence is particularly high in those with diabetes (Hill et al, 2004). Awareness of risk factors, such as atrial fibrillation and carotid stenosis was also low, except for those individuals with these risk factors themselves. In terms of secondary

prevention, only about half of participants knew of the role of medications such as anticoagulants, despite many having attended group meetings for those with stroke (Sloma et al, 2010). Older age, living alone and haemorrhagic stroke were all predictors of lower knowledge about stroke (Sloma et al, 2010).

Another factor may have been the limited stroke specialist follow-up. Nearly half of the 300 people with confirmed stroke, passing through the local acute stroke unit at that time, were discharged directly home with a one-off appointment, with the stroke physician, a few weeks later. General support was provided by the patients' general practitioners, who received a discharge summary from the inpatient stroke team. Those with residual difficulties might be referred to generalist community based rehabilitation. Over recent years, follow up services for stroke have greatly improved, with early supported discharge services and stroke coordinators now widespread. The focus of these services is predominantly on rehabilitation and managing life after a stroke, rather than on secondary prevention.

For those after ischaemic stroke, secondary prevention remains inadequate (Alvarez-Sabin, 2009; Heuschmann et al, 2015). The focus for secondary prevention in stroke is on prescribing medication, such as anti-hypertensives and statins, rather than addressing lifestyle issues (Rudd et al, 2004) and patients' knowledge about risk factors remains poor, particularly in terms of diabetes, atrial fibrillation and physical inactivity (Morse, 2010). Hence, even when appropriate medications are prescribed to the majority, many modifiable risk factors remain, with one recent study finding a high prevalence of smoking, obesity and hypertension at 6 months post stroke (Brewer et al, 2015). The provision of post-stroke services is in marked contrast to those for cardiovascular disease, despite very similar aetiology and many of the same risk and lifestyle factors (Boyle, 2006; Gordon et al, 2004). Comprehensive cardiac rehabilitation, includes both rehabilitation and secondary prevention and has been shown to reduce re-infarction, total and cardiovascular mortality from cardiac and other causes (Heran et al, 2011; Lawler et al, 2011). Cardiac rehabilitation has also been shown to; improve cognitive performance in older adults (Stanek et al, 2011), improve

levels of physical activity, improve quality of life and reduce anxiety and depression (Yohannes et al, 2010).

Cardiac rehabilitation can improve cardiorespiratory fitness, measured by maximal uptake of oxygen (VO₂ max), by as much as 3-4 ml/kg/min in post MI patients (Dressendorfer et al, 1995). It is known that stroke risk is reduced, with an increase in cardiorespiratory fitness, such that an increase in VO₂ max of 3.5ml/kg/min is linked to reduction of 17% in stroke risk (Kodama et al, 2009; Kurl et al, 2003). Sun et al (2013) in a systematic review of physical activity levels in older adults, aged over 60 years, found they were less likely to be regularly active, particularly women. Hence those in the age group most at risk of stroke are likely to start from a low level of cardiorespiratory fitness. A recent Cochrane review, which included nine randomised controlled trials (n=425), identified a mean increase in physical fitness peak, VO₂ max of 2.86 ml/kg/min in intervention groups, compared with controls; there was no evidence that physical fitness training reduced vascular risk after stroke (Saunders et al, 2016). In addition, there was wide variability; in the dose (2-3 weeks to 6 months), patient cohorts (acute <6weeks to chronic >1 year) and length of follow up (immediately after intervention to 12 months); giving little clarity as to the optimum exercise intervention for cardiorespiratory fitness after stroke.

Considering the risk of further vascular problems after stroke, including recurrent stroke, myocardial infarction, dementia, cognitive decline and death, the author hypothesised that there should be multi-factorial programme for stroke, similar to cardiac rehabilitation, which includes exercise, rehabilitation and secondary prevention. Multi-factorial programmes have been successfully used to change behaviour in relation to lifestyle factors in other long term conditions and often include; exercise, education or tailored behavioural interventions, knowledge of perceived risk, and self-management. Self-management interventions usually include; support, education or information provision, and some form of problem solving or goal setting (Lorig & Holman, 2003). It has been shown that self-management interventions can successfully support the type of behaviour change required to modify lifestyle risk factors (Ellis & Breland, 2014) in long term

conditions as varied as; asthma (Newman et al, 2004), type 2 diabetes (Arafat et al, 2016; Norris et al, 2002), metabolic syndrome (Pettman et al, 2008), chronic obstructive pulmonary disease (Chen et al, 2016) , ischaemic heart disease (Taylor et al, 2004) and heart failure (Wright et al, 2003).

The scale of impact can be significant; Gaede et al (2003) found that a programme of exercise, optimum medication and dietary improvements led to an approximate halving in risk of vascular events over more than 7 years in those with diabetes. For non-attendees compared to attendees at cardiac rehabilitation Beauchamp et al (2013) identified a 58% greater long term mortality risk. The challenge is to translate research findings into real world practice; despite the widespread adoption of cardiac rehabilitation, participation in and adherence to cardiac rehabilitation programmes is poor (Jelinek et al, 2015); secondary prevention after cardiovascular disease remains inadequate (Kotseva et al, 2009) with limited medication adherence (Gehi et al, 2007) and poorly controlled lifestyle risk factors (Booth et al, 2014). Robust data, quantifying the reduction in vascular risk after stroke, due to alteration in lifestyle factors, is not yet available. The detailed approach to modifying some risk factors also remains uncertain; however, there is agreement that making lifestyle changes would have a positive impact on recurrent stroke (Furie et al, 2011).

Self-management approaches have been shown to impact on modifiable risk factors found in stroke, such as hypertension (Lakhan & Sapko, 2009; McManus et al, 2010) and medication adherence (Bushnell et al, 2014). A modelling study (Hackam & Spence, 2007) suggested that combining; dietary modification and exercise, with use of anti-hypertensives, statins and aspirin, could reduce the risk of recurrent vascular event after stroke or TIA by up to 80%; further gains could be made through additional medical, surgical and lifestyle interventions including smoking cessation. Although these figures were based on the assumption that all the risk factor modification strategies had an independent effect, it might still be anticipated, that a multi-factorial programme combining self-management interventions to support lifestyle health behaviour change; exercise and medication optimisation, could provide an essential part of vascular risk management after stroke.

The focus for this doctoral practice development project was exploring the development of a multi-factorial programme, which combines exercise, rehabilitation, secondary prevention, and self-management skills, for local people surviving an acute stroke. The focus of this doctoral programme was on identifying the outcomes of such an intervention through primary research and also on the processes supporting the intervention. The intervention was named the 'ASPIRE' programme; an acronym for **A**cute stroke, **S**elf-management support, **S**econdary **P**revention, **I**nformation, **R**ehabilitation and **E**xercise. The first iteration of the intervention started in January 2007 and was initially named 'Life after Stroke'. The programme has continued to run, and is still running in 2017 at the author's NHS trust. In addition, sister 'Life after Stroke' groups are being run, at a number of other local hospitals, by a different NHS provider organisation.

This thesis describes, critically evaluates, and reflects on the development and evaluation of the ASPIRE programme; an innovative, multi-factorial programme, designed to support the self-management ability, of individuals surviving an acute stroke. This once-weekly, twelve week, self-management group programme for stroke survivors and caregivers includes rehabilitation, exercise and a self-management approach to secondary prevention; combining tailored information provision about vascular risk modification and life after stroke, with problem solving and goal setting, plus peer and professional support.

1.6 Overview of subsequent chapters

Chapter 2 is a literature review, which evaluates the existing and evolving literature for programmes, designed to reduce vascular risk through lifestyle change after stroke; thus identifying the evidence base relating to the development of the ASPIRE programme. This literature review is a summary of literature from 2000 to 2016, as viewed from the present day. It should be recognised that the practice development project has been ongoing since 2007 and so has drawn on different literature, as it was published, throughout the process.

In **Chapter 3** the methodology used, for both the practice development project and the two phase research evaluation, are justified through critical evaluation of

relevant literature. A Plan-Do-Study-Act (PDSA) structure (Taylor et al, 2013) was used for the practice development, nested within a practice development ethos, and supported by a framework of complex intervention methodology (Craig et al, 2008). Outline methods for both the practice development project and the primary research evaluation, are then discussed.

Chapter 4 presents, analyses, and discusses the findings of the practice development project, plus the two phase primary research evaluation. The practice development project consisted of 5 PDSA cycles, spanning six years, and the two phases of the research evaluation. Phase 1, of this mixed methods research evaluation, involved interviews to identify the impact of participating in ASPIRE from the perspectives of; a cohort of stroke survivors, their caregivers and the professional staff and volunteers involved in running the ASPIRE programme. The participant interviews were analysed, using a grounded theory approach, to identify key themes, in order to search for standardised, validated tools to capture that impact. Phase 2 of the research evaluated the ability of those identified validated tools, to capture the impact of the ASPIRE programme, on a further cohort of participants.

In **Chapter 5**, the author reflects on her learning, through listening to and working with stroke survivors and their caregivers, to develop an interpretive, theoretical framework, to guide the implementation of these processes in clinical practice. The reflections in this chapter draw on, and from; data collected for the research and the practice development phases of this doctoral programme, plus evidence from field notes, gathered in the author's practice development diary, 'praclog', and research diary, 'doclog'.

In **Chapter 6** a reflexive, integrative review of the author's doctoral developmental journey is presented, including an evaluation of how this will impact the author's future clinical practice and consultant physiotherapist role. This chapter includes; dissemination to date, areas for future research and **summarises the overall original contribution to knowledge, of this doctoral**

thesis, on supporting life after stroke, in terms of rehabilitation (“A life I like”) and secondary prevention (“A life to live”).

Key dates, for the different stages of the doctoral process within this thesis, are highlighted in Table 2.

Table 2: Key dates during doctoral process

| Activity | Date |
|---|---------------------------|
| Enrolment for Professional doctorate with initial aims: <ul style="list-style-type: none"> • Systematic review; What is the evidence for supported self-care in people with neurological conditions? • Research enquiry: Does current clinical practice after stroke support self-care?: Perceptions of stroke survivors and clinicians. • Practice development project; Can self-care be supported after stroke from an acute hospital setting? | September 2006 |
| First PDSA cycle. | Autumn 2006 to April 2007 |
| First ‘Life after stroke’ group held. | Jan to April 2007 |
| Second PDSA cycle. Programme now named ASPIRE. | April to October 2007 |
| Third PDSA cycle | 2008-2009 |
| Ethics approval for 2 phase primary research project 08/H0205/14 investigating outcomes of attending the ASPIRE programme. | May 2008 |
| Transfer | December 2008 |
| Phase 1 data collection from patient and caregivers, transcription & analysis | End 2008 – End 2009 |
| Fourth PDSA cycle. Phase 1 data collection from staff and volunteers, transcription & analysis | 2009-2010 |
| Fifth PDSA cycle. Phase 2 data collection & analysis | 2010 – 2012 |
| Writing & reflection. | 2012-2014 |
| Submission of thesis & viva | March & June 2014 |
| Submission of revised thesis | June 2016 |
| Final submission of corrected thesis | June 2017 |

Chapter 2 – Review of the Literature

2.1 Introduction

This chapter presents a structured critical review of the existing and evolving literature, in relation to multi-factorial programmes designed to reduce vascular risk after stroke, thus identifying the evidence base relating to the practice development project i.e. the ASPIRE programme. This literature review is a summary of literature, from 2000 to 2016, as viewed from the present day. It should be recognised that the practice development project has been ongoing since 2007 and so has drawn on different literature, as it was published, throughout the process. The search terms used for this literature review are identified in the search strategy (section 2.2).

2.2 Search strategy

Research, professional literature and policy documents were sourced, using key databases; MEDLINE, Science Direct, CINAHL and Web of Science. In addition, SCOPUS was used to identify other relevant literature.

The search was limited to peer reviewed publications, in English, between 2000 and 2016. A start date of 2000 was chosen as this was the year that stroke services started to significantly change, following the first national clinical audit for stroke (Rudd, 1999) and the publication of the first national clinical guidelines for stroke (Intercollegiate stroke working party, 2000). The Boolean search terms used to identify multi-factorial programmes designed to reduce vascular risk after stroke, (with truncations denoted by*) were:

(Stroke* or Cerebrovascular* Or Cerebral vascular* or Ischemic stroke* or TIA or vascular) in Title

AND (Prevent* or Reduc* or Manag* or Car*e or modif*) in Title

AND (Recur* or Vascular risk* or risk*) in Abstract

AND (Programme* or Exercis* or Educat* or Rehabilitat* or Inform* or Adv* or Manag*) in Abstract

Of the 1902 hits, 1840 studies were excluded by title, as irrelevant to the review question. The abstracts, of the remaining 62 articles identified, were read to ascertain relevance and manual searches, of the reference lists of the articles retrieved, were searched to identify additional relevant articles. A total of 29 studies, relating to multi-factorial programmes to reduce vascular risk post-stroke, were identified and are critically reviewed in section 2.3.

2.3 Multi-factorial programmes to reduce vascular risk post-stroke

The 29 studies differed in a number of variables including; methodology, participant characteristics, locations, settings, interventions, outcomes and length of follow up. Similarities and differences, between the studies, were analysed and are summarised, in Table 3 at the end of this chapter. A number of published protocols were also identified, which are ongoing, or have no published results that can be found. These are summarised in table 4 at the end of this chapter.

Methodology, including settings, recruitment and outcomes measured

The majority, of the completed studies (20/29), were randomised, controlled trials using parallel group, cross-over, cluster design or waiting list controlled. Due to the nature of the intervention, participants could not be blinded to their group allocation; however, in the majority of cases, there was a blinded assessor (e.g. Harrington et al, 2010; Ihle-Hansen et al, 2014). Of the randomised, controlled trials, only Cadilhac et al (2011) had an attention equivalent control group; hence, the results demonstrated by the other studies, could be due to the additional support received by stroke survivors i.e. a Hawthorne effect. The vast majority had small sample sizes $N < 100$, and had been designed as pilot or feasibility studies, not powered to give statistically significant results. The remainder were of prospective, pre-post intervention design, so had no control group to be able to separate intervention effect, from spontaneous recovery (Kamm et al, 2014).

For the studies in acute stroke or TIA, these small numbers reflect the relatively small numbers coming through, even a large stroke unit, at any one time. The small numbers also reflect the difficulties, recruiting in a timely way, from a patient group still in shock. For the studies where the intervention required

attendance at a specific venue in the first month, when not allowed to drive, the pool of potential participants would be restricted to those with access to transport through family members, or an effective public transport system. Due to the lack of systematic follow up long term after stroke, many of the studies in chronic stroke relied on recruiting volunteers, through sources such as; community and voluntary organisations, stroke clubs and newspaper advertisements; again leading to low numbers.

The length of time since TIA or stroke, before being recruited into a study, varied. Nine studies recruited participants relatively soon following stroke or TIA, within the first 3 months, with two studies recruiting participants whilst still in the inpatient stroke unit (Holzemer et al, 2011; Evans-Hudnall et al, 2012). A further 8 studies were sub-acute, i.e. between 3 and 12 months after stroke. Participants in 8 of the studies were described as chronic or late stage stroke, and were between 1 and 5 years after stroke, or only specified a history of stroke (Anderson et al, 2013), or symptomatic vascular disease including stroke (Sol et al, 2008), without indicating timescale since event.

Geographically the studies were fairly widely distributed; with 9 of the 29 studies conducted in the USA or Canada, 6 in Australia or New Zealand, 6 in the UK or Ireland, 5 in mainland Europe and the remaining 3 in Asia. Settings varied from inner city New York to rural Australia, and venues for intervention varied from; acute hospital, to community venues and the patients' own homes, though none of the studies included participants living in residential nursing care homes. Despite the wide variety of locations and settings, some of the issues identified in these studies were also issues in the author's locality; including a scattered, rural population (e.g. Huijbregts et al, 2008; Marsden et al, 2010), challenges with transport, and relatively small numbers at any one time.

The multifactorial and variable nature of the interventions meant that outcome tools used in each study also varied greatly, making comparison between studies very difficult, and providing little guidance on the best outcome measures to use. Some reported on feasibility, recruitment, attendance, drop out and completion rates (e.g. Cadilhac et al, 2011; Anderson et al, 2013); some measured

physiological parameters such as blood pressure, blood cholesterol levels and VO₂ max (e.g. Joubert et al, 2008; Tang et al, 2010; Kronish et al, 2014); others assessed stroke knowledge, stroke risk behaviours or cardiac risk scores (e.g. Gilham & Endacott, 2010; Evans-Hudnall et al, 2012; Anderson et al, 2013; Kirk et al, 2014) and still others measured mood, quality of life, function or reintegration (e.g. Huijbregts et al, 2008; Gilham & Endacott, 2010; Harrington et al, 2010; Ihle-Hansen et al, 2014; Kamm et al, 2014).

In light of the life-time increase in risk, of recurrent vascular event, even after minor stroke or TIA (van Wijk et al, 2005), it is critical that any multi-factorial programme, that aims to reduce vascular risk, has a long term impact. The timescale, from baseline to final follow up, was relatively short in most studies, with some only following up till the end of the intervention period, or a few weeks after; six studies following up for 6 months after, and only eight studies following up for a year. Although some studies were able to show a reduction in cardiac risk score (Lennon et al, 2008); Kirk et al, 2014), none of the studies reviewed were powered to identify a significant difference in recurrent stroke or death. To be able to identify a statistical reduction in morbidity and mortality, would require very large numbers, and / or a long term follow up, such as the prospective, multicentre, randomised, controlled trial underway by Joubert et al (2015), which plans to recruit 1000 patients, and follow up for one year.

Participants

Overall the studies included; participants with cerebrovascular disease with an age range of 49.6 years +/- 10.7 years (Evans-Hudnall et al, 2012) to 72.6 +/- 11.2 years (Ihle-Hansen et al, 2014), with the majority of participants, in most studies, aged between 60 and 70 years old. Only Evans-Hudnall et al (2012) identified the inclusion of an ethnic minority population. The remaining studies did not specify the ethnic mix, so are likely to represent the local indigenous populations i.e. predominantly Caucasian, excepting the three Asian studies (Sit et al, 2007; Kim et al, 2013; Fukuoka et al, 2015). Overall, the patients in these studies are not too dissimilar, from those in author's locality, so the studies in this review are relevant.

It has been shown that support by next of kin, is associated with increased adherence to secondary prevention medication (Glader et al, 2010), and a change in behaviours, such as; levels of smoking, physical activity and healthier eating patterns. It is not known whether, involvement in a post-stroke intervention, affects the ability of the next of kin, to provide that support. Several studies involved caregivers, partners or family members in the intervention to some extent, but did not measure the impact (Huijbregts et al, 2008; Ireland et al, 2010; Marsden et al, 2010; Wolfe et al, 2010; Kim et al, 2013; Ihle-Hansen et al, 2014).

Three studies, (Harrington et al, 2010; Kim et al, 2013; Tielemans et al, 2015) measured outcomes for caregivers, as well as involving them. Harrington et al (2010) encouraged family members and caregivers to help in the exercise hour, each week, of their 8 week intervention, and also provided a dedicated session with the health psychologist, but found no evidence of a difference, in terms of Carer Strain Index. In the study by Kim et al (2013), caregivers as well as stroke survivors, participated in a web-based stroke education programme which led to an increased sense of caregiver mastery. In contrast, Tielemans et al (2015), included caregivers as full participants, with their own goals, in their 10 week self-management intervention, and found significant improvement in partners' proactive coping, and also a trend towards increased self-efficacy in partners. There is insufficient evidence in this review, to guide the involvement of family members or caregivers, in a multi-factorial programme, to reduce vascular risk after stroke.

Sol et al (2008) included those with symptomatic, vascular disease including stroke; Anderson et al (2013) included veterans with a history of stroke or multiple risk factors for stroke; and Joubert et al (2008) included those with haemorrhagic stroke and ischaemic stroke. Fourteen studies included TIA as well as stroke, with 8 of the studies focusing only on those with TIA or minor / mild or non-disabling stroke. Thirteen studies included only those with ischaemic stroke, or did not specify stroke type, and most excluded those with cognitive or communication impairment; with only Cadilhac et al (2011) specifying that they included those with severe stroke, including language and cognitive impairments.

The bias towards studies that focused on TIA or non-disabling or minor stroke is likely to be because this group, have a high risk of a recurrent stroke, which is often disabling or fatal. In addition, those whose stroke has left them with residual impairments are a more heterogeneous group, potentially more difficult to plan, and run a programme for, and most likely requiring higher numbers to demonstrate statistical effectiveness, due to an increased number of variables. Those with residual impairments also need an effective means of reducing their vascular risk, since; despite their risk of further stroke being relatively lower than those with TIA or minor stroke, the risk of cognitive decline or vascular dementia remains, and the risk of myocardial infarction may be higher, due to relative inactivity. It has been shown that stroke survivors living in the community, have cardiorespiratory fitness levels markedly lower (26 – 87%), than healthy age and gender matched controls (Smith et al, 2012). Furthermore, many stroke survivors become less physically active in the year following their stroke (Hornnes et al, 2010), so are likely to become less physically fit.

Those with residual weakness, hemiplegia or incoordination, may find it more difficult to increase physical fitness. This cannot be substantiated from this review of the literature, as of the studies that included exercise as part of the intervention, four only included those with minor stroke or TIA, and most of the rest provided insufficient detail about physical abilities of participants. It is therefore unclear what level of physical impairment participants had; though Tang et al (2010) included information about the type of gait aids used, the need for higher staffing ratios and the need to use alternative equipment such as a recumbent bike, which gave some indication. Those with residual physical impairments, may also be less willing to participate in multi-factorial interventions that include exercise, however; this cannot be determined from the literature in this review, as all of the studies, that did not exclude those with residual impairments, sought volunteers to participate in the study (Huijbregts et al, 2008; Lennon et al, 2008; Harrington et al, 2010; Marsden et al, 2010; Tang et al, 2010; White et al, 2013).

Those with residual impairments may require a different approach to the self-management aspects of a multi-factorial programme, as impairments such as memory difficulties and dysphasia, make information provision, problem solving

and goal setting, more challenging. The only study to specify that they included those with cognitive and communication impairments (Cadilhac et al, 2011), found a positive trend in outcomes, rather than a statistically significant change in the intervention group (stroke self-management group), though this was probably due to the small numbers involved. Overall, there is insufficient evidence, provided in these studies, to guide a multi-factorial programme, to reduce vascular risk, in participants with residual physical, cognitive or communication deficits, at any point after TIA or stroke.

Intervention

The designs and mechanism of delivery of the interventions varied, with some taking more of a traditional medical model (Lennon et al, 2008; Kirk et al, 2014), with a didactic approach to information provision. The majority used a biopsychosocial model, with the emphasis on; self-management, locus of control, empowerment and self-efficacy (Jones, 2006), and usually included the main self-management components; i.e. education / information; problem solving / goal setting / action planning; and support (Lorig & Holman, 2003). In terms of exercise, although all of the interventions emphasised the importance of increasing physical activity, only 10 included exercise as an integral part of the intervention. Of these, six were for those with chronic stroke (Lennon et al, 2008; Huijbregts et al, 2008; Tang et al, 2010; Marsden et al, 2010; Harrington et al, 2010 and White et al, 2013) and the remaining four were for those with TIA or minor / non-disabling stroke (Prior et al, 2011; Faulkner et al, 2012; Kirk et al, 2014 and Kamm et al, 2014).

There was significant variation in terms of the education or information provision component of the intervention, and many used multiple strategies. Some involved individual discussions with stroke specialists, face to face (e.g. Gilham & Endacott, 2010) or by phone (e.g. Anderson et al, 2013); some involved the use of workbooks (e.g. Jones et al, 2009; Evans-Hudnall et al, 2012); some had interactive group discussions, led by professionals (e.g. Faulkner et al, 2012, 2015), jointly led by professionals and peers (Cadilhac et al, 2011), peer-led (Kronish et al, 2014) or facilitated by trained volunteers (Harrington et al, 2010);

and some used technology, such as videoconferencing and web-based information (e.g. Anderson et al, 2013; Kim et al, 2013)

The problem solving, goal setting and action planning components of the interventions, though not always clearly articulated, were also approached in a variety of ways; including individual sessions with stroke specialists (e.g. Evans-Hudnall et al, 2012), or trained volunteers (Harrington et al, 2010), or as part of the group education sessions (e.g. Sol et al, 2008; White et al, 2013) and were supported by workbooks, diaries or record cards (e.g. Joubert et al, 2008; Jones et al, 2009; Holzemer et al 2011; Fukuoka et al, 2015). Only Huijbregts et al (2008) recorded goal achievement, as an outcome measure.

For nearly all of the interventions, the support element was provided by healthcare professionals. Seventeen of the interventions also included a group component, providing the opportunity for peer learning and support. Mostly, this was face to face, though Anderson et al (2013) used videoconferencing. There was wide variation in contact time, frequency and duration of the interventions, with the group based programmes providing the most input. The majority of these group based interventions, were held over a 6 to 12 week period, with sessions twice a week. This is likely to translate to increased cost of providing the intervention, however; only Harrington et al (2010) carried out an economic analysis, calculating the cost per patient as £99, so the cost-benefit of the other interventions is unknown. A number of studies claimed potential cost-benefits for their interventions. For instance Kamm et al, (2014) stated they assumed their intervention would be cost effective, based on its similarities to comprehensive cardiac rehabilitation. As their study included participants early after stroke or TIA, when natural recovery is likely, and no control group, this assumption cannot be justified. Similarly Kendall et al (2007) suggested that there were substantial cost savings possible, as there was less of a decline in their intervention, than their control group, however; as the two groups were not controlled for stroke severity, comorbidities or disability levels, then these factors may have contributed, to the difference between the two groups.

In most of those programmes without a group component, the focus was on providing additional health professional support and follow up, using self-management strategies to supplement usual care (e.g. Evans-Hudnall et al, 2012; Leistner et al, 2012). A number of interventions were also designed to improve communication between stroke specialist services and primary care (Joubert et al, 2008; Ihle-Hansen et al, 2014). None of the studies compared a group based intervention, including peer support, with an attention equivalent, health professional, support intervention, so it is unclear whether it is the quantity of support, or the type of person providing the support, that has an impact.

Due to the variable combinations and types of delivery, and the huge variety of outcome tools used, it is very difficult to attribute the outcomes to the different components of self-management, in the interventions reviewed here. Some interventions have demonstrated statistically significant improvements in; stroke knowledge (Evans-Hudnall et al, 2012; Anderson et al, 2013), self-efficacy (Anderson et al, 2013) and behaviour in relation to some lifestyle risk factors (White et al, 2013; Kamm et al, 2014), although; results have to be interpreted with caution, due to lack of an attention equivalent control group in most studies, thus the possibility of a Hawthorne effect. Others have been unable to identify statistically significant evidence of positive changes, though this could be due to small numbers, making the studies underpowered to detect change (Cadilhac et al, 2011).

Despite being novel interventions, only three studies had an additional qualitative arm to seek participant views (Ireland et al, 2010; Anderson et al, 2013; White et al, 2013). As the majority of studies did not include a qualitative arm to seek participants' views, proxy measures of participant views of the interventions have to be considered, when using the evidence to guide the development of a new intervention. These include; high levels of adherence to the interventions (Cadilhac et al, 2011; Anderson et al, 2013) or alternatively low levels of adherence (e.g. Holzemer et al, 2011), participants being lost to follow up (e.g. Harrington et al, 2010; Wolfe et al, 2010), or declining to participate in some studies (e.g. Faulkner et al, 2012) and the reasons e.g. death or lack of transport. These proxy measures could be misleading, however; as 65% of those in the

control arm of Harrington et al (2010) were offered, and took part in, the intervention after the study completed.

Those studies advising on increasing physical activity, rather than including it in the intervention, either found no significant improvement in exercise behaviours (Evans-Hudnall et al, 2012; Anderson et al, 2013), or found; self-efficacy towards extra exercise increased (Sol et al, 2008), self-reported physical activity increased (Joubert et al, 2008; Gilham & Endacott, 2010; Kim et al, 2013) or self-reported exercise tolerance increased (White et al, 2013). As none of these studies directly measured physical fitness as an outcome, it should be considered that these results may reflect a social desirability effect. The remaining studies, that did not include exercise as part of the intervention, made no comment about levels of physical activity.

Studies including exercise as part of the intervention found significantly increased mobility (White et al, 2013; Kamm et al, 2014); physical integration or physical functioning (Harrington et al, 2010; Kirk et al, 2014; Kamm et al, 2014); higher enrolment in community exercise programmes (Huijbregts et al, 2008) and significantly increased aerobic or cardiorespiratory fitness or exercise capacity (Lennon et al, 2008; Tang et al 2010; Prior et al, 2011; Faulkner et al, 2012, 2015; Kamm et al, 2014; Kirk et al, 2014). Tang et al (2010) in a pre-post intervention, found a significantly improved VO₂ max, despite including a substantial amount of home exercise in their intervention, such that 80% of the exercise sessions were unsupervised. All of these studies, either included TIA or acute minor non-disabling stroke or chronic stroke, with or without residual deficits, so the impact of an intervention, including exercise, on those with recent stroke leading to residual deficits, is not known.

A number of other statistically significant findings have been identified including; improvements in body mass index, weight or waist circumference (Joubert et al, 2008; Prior et al, 2011; Kamm et al, 2014), reductions in blood pressure (Joubert et al, 2008; Ireland et al, 2010; Leistner et al, 2012; Faulkner et al, 2012, 2015; Kronish et al, 2014; Kamm et al, 2014) and improvements in blood cholesterol (Prior et al, 2011; Leistner et al, 2012; Kamm et al, 2014). These improvements

could potentially be linked to the self-management aspects of the interventions, or the exercise component, or both. Statistically significant improvements in mood were only demonstrated with an intervention that included exercise (Lennon et al, 2008).

Table 3: Multi-factorial programmes to reduce vascular risk post-stroke

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|------------------------------------|---|--|
| Anderson et al (2013). USA | Mixed methods pilot evaluation. Phase 1 interviews, questionnaires & focus groups. Phase 2 feasibility study. N=37 Veterans with a history of stroke or multiple risk factors for stroke. Phase 1 age 60 +/- 9 years, phase 2 age 62 +/- 7 years. Intervention: 6 weekly sessions of self-management classes and clinic visits by video conferencing, plus 1-2 individual telephone counselling sessions. Topics covered; understanding individualised stroke risk, action plans, problem solving, diet, exercise, taking medications, cognitive symptom management, and communication with health professionals. Outcome measures at baseline, 12 & 18 weeks. | Attendance 87% Significant increase in self-efficacy at 12 weeks, significant increase in stroke risk knowledge, significant improvement in communication with healthcare providers, no significant improvements in exercise behaviours. No control group. Possible Hawthorne effect |
| Cadilhac et al (2011) Australia | Randomised controlled trial N=143. Stroke survivors at least 3 months post stroke, including those with severe stroke, including language & cognitive impairments. Age 69 +/-11 years. 2.5 hours for 8 weeks stroke self-management, education only programme compared to 6 week generic, self-management education programme and also compared to usual care. Outcome measures at baseline, post intervention and 6 months post intervention | Safe & feasible. Greater participation & completion rates >90% than generic programme 69%. Non-significant trend towards positive & active engagement in life & improvement in anxiety & depression. Attention control group. |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|---|---|--|
| <p>Evans-Hudnall et al (2012) USA</p> | <p>Randomised controlled trial N= 52. TIA or stroke in those from minority ethnic background and of low socioeconomic status recruited from stroke inpatient setting. Age 56 +/- 9.9 years (intervention), 49.6 +/- 10.7 years (control). Usual care or 'STOP' programme intervention. Intervention consisted of three 30-45 minute cognitive behavioural therapy focused self-care sessions, one as an inpatient, the other two via phone. Components included self-monitoring, goal setting, problem solving, social support, stress management. Also a workbook with information about stroke, risk factors, resources, exercise and diet tracking. Outcomes measured at baseline and 4 weeks.</p> | <p>Significant between group differences in stroke knowledge, tobacco use and improved alcohol use. Link found between increased anxiety at baseline and tobacco use. No significant changes found in fruit and vegetable consumption or exercise.</p> |
| <p>Faulkner et al (2012), (2015) New Zealand.</p> | <p>Single centre randomised controlled trial. N=60 TIA or non-disabling stroke within 7 days of symptom onset. Age 69+/- 11 years 8 week intervention or control group. Intervention: health enhancing physical activity programme (HEPAP). 2 x 90 minute group exercise sessions, 3-5 participants (15 minutes walking, 5 minutes cycling, 60 minutes resistance training, core stability, posture and flexibility. 1 x 30 minute didactic facilitated group discussion, in line with health belief model of health behaviour change. Topics were vascular risk factors, stroke prevention, nutrition, blood pressure, medication adherence, and stress management, emotional and behavioural changes. Measures at baseline, immediately after intervention and at 3 months.</p> <p>Also single centre RCT N=55 TIA or non-disabling stroke, within 7 days of symptom onset. HEPAP vs usual care with 12 month follow up</p> | <p>97 invited to participate, 37 declined or could not be contacted. Intervention group participants attended 94% of exercise sessions. 3 drop outs (1 control, 1 intervention) Significantly greater reduction in systolic BP and increase in aerobic fitness, post intervention & sustained at 3 months. No long term follow up</p> <p>Improved perceived health and wellbeing, maintained at 12 months. No difference in HADS scores.</p> |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|--------------------------------|---|--|
| Fukuoka et al (2015) Japan | <p>Multicentre, parallel group, stratified (stroke subtype) randomised, controlled trial. N=321.</p> <p>Ischaemic stroke or TIA within one year of onset</p> <p>Age 67.3 +/- 8.5 years</p> <p>Usual care vs 6month disease management programme intervention, face to face and phone based education, booklets, self-management record notebook, goal setting related to diet, exercise and life purpose goals, self-monitoring, adjustment of medication in relation to physiological indicators.</p> <p>Outcomes: stroke recurrence & stroke death.</p> | <p>Trial completed 2015.</p> <p>Baseline features article published, no results yet.</p> |
| Gilham & Endacott, 2010. UK | <p>Single blind randomised controlled trial. N=52.</p> <p>First time TIA or minor stroke.</p> <p>Age 68.3 control group 68.9 +/- 13.2, intervention group 67.7 +/- 12.0</p> <p>Usual care vs enhanced secondary prevention (further information about stroke, explanation of individual stroke risk factors, and a motivational interviewing discussion about behaviour change intentions, with development of a plan for behaviour change plus telephone support follow up at 2 & 6 weeks).</p> <p>Outcomes measured at baseline and 3 months</p> | <p>No statistical difference in readiness to change behaviour.</p> <p>Significant improvements in self-reported fruit and vegetable consumption & exercise.</p> <p>No difference in alcohol consumption or mood.</p> <p>No long term follow up</p> |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|---|---|---|
| Goldfinger et al (2012). Kronish et al (2014) USA | <p>Randomised wait-list controlled trial. N=600. Stroke or TIA within previous 5 years from ethnically diverse, low income communities.</p> <p>Age 63 +/- 11 years.</p> <p>Intervention was a 90 minute, once weekly, 6 week, peer led, community based, stroke prevention, self-management group workshop based on chronic disease self-management programme (Lorig et al, 2001).</p> <p>Didactic education, action planning, feedback, social persuasion, education materials.</p> <p>Topics: what are strokes and mini strokes, preventing future strokes: BP, LDL cholesterol, blood clumping, Medicine responsibilities, working with your healthcare team.</p> <p>Outcome measurement at baseline and 6 months.</p> | <p>Small improvement in blood pressure, particularly systolic (4mmHg).</p> <p>No change in low density lipoprotein (LDL) cholesterol or antithrombotic use.</p> <p>20% of intervention group and 11% wait list group lost to follow up.</p> <p>Average attendance 4 out of 6 workshops.</p> |
| Harrington et al (2010). UK | <p>Single blind, parallel group, randomised, controlled trial. Geographical block randomisation. N=243</p> <p>Participants living in the community, median 10.3 months after their stroke.</p> <p>Age 70 +/- 10.2 (control) 71 +/- 10.5 (intervention).</p> <p>Partners, carers & family members also encouraged to attend.</p> <p>Self-management programme of 1 hour exercise, 1 hour interactive education twice weekly for 8 weeks plus goal setting, home exercise manual, directory of local resources. Trained volunteers supported the programme with goal setting and facilitating education sessions. Session for family members and carers with health psychologist.</p> <p>Outcomes measured at baseline, 9 weeks (post intervention), 6 & 12 months.</p> <p>Included an economic evaluation.</p> | <p>Significantly improved physical integration at 9 weeks maintained for one year.</p> <p>Significant improvement in psychological component of quality of life score.</p> <p>Loss of 38/119 control, 31/124 intervention.</p> <p>No attention equivalent in control group. Possible Hawthorne effect.</p> <p>Include intention to treat and per protocol analysis.</p> |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|------------------------------------|--|--|
| Holzemer et al (2011) USA | Single centre randomised controlled trial. N=52. TIA & acute ischaemic stroke. Age 59.3 +/- 10.4 (intervention group); 65.8 +/- 12.9 (control group). Recruited during acute inpatient stay. Standard care vs , intensive education & risk reduction plan including diet, exercise, smoking cessation and medication adherence. Follow up at 6 weeks and 3 months. | Large numbers of drop outs 10/25 from control group, 15/27 from treatment group. Improved self-report card of medication compliance, smoking, diet, exercise, BP, body mass index and cholesterol results in intervention group. No long term follow up. |
| Huijbregts et al (2008) Canada. | Pre-post evaluation of a standard life after stroke education programme with a new self-management programme with exercise (Moving on after Stroke 'MOST'). N=30. (+16 carers). Chronic stroke average 2 years post stroke. Age 68 years. MOST - is a self-management programme for persons with stroke and their carers. 1 hour exercise, 1 hour discussion twice weekly for 9 weeks. Exercise included warm up and cool down, plus either 40 minutes cardiovascular, or 40 minutes strength and balance exercise. Outcome measures at baseline, completion of intervention & 3 months. | Significant improvement in reintegration to Normal Living Index. 78% of all short term personal goals achieved. Statistically significant higher percentage enrolled in community exercise programmes. No long term follow up. |
| Ihle-Hansen et al (2014) Norway | Randomised, parallel group, evaluator blinded, controlled trial. N=195. Acute stroke or TIA. Age 72.6 +/- 11.2 (intervention), 70.6 +/- 13.6 (control). Usual care vs intensive vascular risk factor intervention. Individually tailored advice on risk of stroke recurrence, prognosis and rehabilitation by stroke nurse and medication optimisation by stroke physician at 3 & 6 months through clinic attendance. Treatment plan sent to GP Patients' carers included as needed. Smoking cessation offered, physical activity encouraged, diet & alcohol use advised. Group strength and balance training offered. Physiotherapists, dietician, occupational therapist and social worker contacted as needed. Outcome measures at baseline, 1 year. | No effect on incidence of cognitive symptoms demonstrated. Association with lower HADs scores and lower prevalence of depressive symptoms. Loss of 13/98 from intervention group, 4/97 from control group. |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|--------------------------------|---|--|
| Ireland et al (2010) Canada | Pilot, mixed methods study, Prospective cohort, pre-post design plus qualitative analysis of clinic notes and questions to patients N=20. Recent probable TIA or confirmed stroke. Age 67.5 +/- 16.1. Usual care vs expanded nurse case management – additional clinic visits & phone calls (4.8 hours over 6 months) including motivational interviewing & self-management approaches, home monitoring equipment, simplification of medication routines, memory cues, discussion of lifestyle changes including increased activity, dietary changes including alcohol reduction, weight loss, smoking cessation, medication adherence. 2 hour group stroke prevention class for stroke survivors & family members. Measures at baseline and 6 months. | Feasible. Significant reductions in BP, increases in medication & self-efficacy. Qualitatively – medication knowledge gaps, gaps in communication around transition of care, positive changes to healthy lifestyle behaviours. |
| Jones et al, (2009). UK | Multiple-participant, two phase, single subject design. N= 10 On average 24.2 weeks after first stroke. Age 61.5 +/- 8.2 Intervention: individualised self-management workbook based on self-efficacy principles, with sections to increase mastery, vicarious experience, & feedback plus goal setting / action planning. Intervention introduced at randomly generated time-point. | Statistically significant improvement in stroke self-efficacy questionnaire and recovery locus of control scale scores over 14 weeks. No long term follow up. No control group – each participant acted as their own control. |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|-----------------------------------|---|---|
| Joubert et al (2008) Australia | <p>Pilot randomised, controlled trial. N=186. Recent (<3 months) ischaemic or haemorrhagic stroke or TIA.</p> <p>Age 63.4 +/- 13.7 (intervention), 68.2 +/- 12. (control).</p> <p>Usual care vs ICARUSS (integrated care for the reduction of secondary stroke).</p> <p>Minimum 4 x 3 monthly appointments with GP, preceded by telephone follow up by stroke coordinator, risk factor management chart including goals and recommendations for management of risk factors sent to GP and hand-held risk factor profile for patient, educational pamphlets, diary booklet to record BP and walks.</p> <p>Outcome measurement at baseline and 12 months.</p> | <p>233 enrolled, 32 lost to follow up in intervention group, 15 from control group.</p> <p>Significant difference in BP, Body Mass Index, number of walks taken, quality of life.</p> <p>Decrease in disability (modified Rankin) in intervention group.</p> <p>Did not use intention to treat analysis.</p> |
| Kamm et al (2014) Switzerland | <p>Prospective, interventional, single centre, pre-post, cohort study. N=105.</p> <p>TIA or stroke with no or minor residual deficits within previous 42 days (median).</p> <p>Age 56.7 +/- 10.9 years.</p> <p>Only 20% of those invited to attend accepted.</p> <p>Intervention was a 3 month, twice weekly, hospital based, secondary prevention and neurorehabilitation, outpatient programme in groups of 4-8 patients. Tuesday 60 minutes aerobic + 1 hour physiotherapy including balance, coordination, mobilisation, weight training, fine motor skills. Thursday 45 minute aerobic + 1 hour lecture & counselling – aetiology, diagnosis, treatment & prevention of stroke, vascular risk factors, nutrition, smoking cessation, psychological coping strategies.</p> <p>Outcome measurement at baseline and 3 months.</p> | <p>Feasible to integrate this group of patients into an existing comprehensive cardiac rehabilitation programme. Significant improvement in exercise capacity, smoking status, BP, BMI, LDL, triglycerides, 9 hole peg, 6 minute walk test, one leg stand & HRQOL.</p> <p>Loss to follow up of 10 patients.</p> <p>No control group and early after TIA or stroke so outcomes seen may be due to spontaneous recovery or Hawthorne effect rather than intervention.</p> |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|-------------------------------------|---|---|
| Kendall et al (2007). Australia. | Randomised, controlled trial. N=100. Stroke in previous few months. Age 66 +/- 10.7 years. Group programme of self-management skills development, once weekly, for 2 hours, for 6 weeks based on existing Chronic Disease Self-Management course (Lorig et al, 2001) plus additional week with stroke specific session. Topics included healthy eating, exercise and relaxation. Outcomes measured at baseline, 3, 6, 9 & 12 months. | Intervention group showed less of a decline in aspects of Stroke Specific Quality of Life scale, no impact on self-efficacy or mood. Short term impacts only. 29/100 dropped out over the year. 37/58 in intervention group attended 4 or more sessions. Minimal information about clinical status of participants e.g. stroke severity, disability levels, cognition, communication, comorbidities so unclear whether all variables accounted for. |
| Kim et al (2013) Korea | Randomised, controlled feasibility study. N=36 Ischaemic stroke within previous 1 -12 months and their caregivers. Age 63.9 +/- 7.4 (control), 67.4 +/- 7.3 (intervention). Web based, stroke education programme for 9 weekly sessions. Video based lectures, quizzes, feedback on self-report of health behaviours, ability to network with health professionals, links to websites with stroke information. Topics included stroke recurrence, exercise, fall prevention, medication adherence, nutrition management, smoking & drinking, control and prevention of hypertension & diabetes, control of emotions and formation of family intimacy Outcome measures at baseline and 3 months. | Feasible intervention for those with access to internet. 63.1% participation in web based programme. Increased sense of control, health motivation and caregiver mastery. Self-reported positive changes in exercise behaviour & diet. No change in smoking, alcohol consumption or blood lipid profile. Limited conversion to participation due to limited internet access. |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|----------------------------------|--|--|
| Kirk et al (2014) UK | <p>Single blind, randomised, controlled trial. N=24.</p> <p>TIA and minor stroke only.</p> <p>Age 66.8 +/- 7.3 years (control), 67.5 +/- 11.4 years (intervention).</p> <p>Standard care vs standard care plus attendance once weekly, for 8 weeks, a comprehensive cardiac rehabilitation programme of exercise and education.</p> <p>Outcomes measured at baseline and 6 months; SF36, HADS Cardiovascular disease risk score, resting blood pressure, blood glucose, obesity, self-reported physical activity levels, smoking and daily reported portions of fruit and vegetables.</p> | <p>Feasible for those with TIA or minor stroke to attend standard cardiac rehabilitation programme.</p> <p>Group comparison with independent t-tests.</p> <p>Statistically significant improvement in cardiac risk score, activity levels, physical functioning and mental health.</p> <p>Lack of attention control so possible Hawthorne effect.</p> <p>Self-reported activity levels are subject to social desirability bias.</p> |
| Leistner et al (2012) Germany | <p>Two part study. Part A prospective observation, N= 168.</p> <p>Part B modelled secondary prevention programmes at 3 different levels, with different frequency and content of input. N=173.</p> <p>TIA and minor stroke only.</p> <p>Age 64.7 +/- 11 years Part A, 67.6 +/- 10 years, part B.</p> <p>Level 1 included motivational interviewing, blood pressure, and physical activity, medication, smoking cessation, nutrition and visits at 6 weeks, 3 months and 6 months.</p> <p>Level 2 also included information sent to primary care.</p> <p>Level 3 also included visit at 3 weeks, 24 hour BP and additional counselling at baseline.</p> <p>Outcome measures at baseline and 6 months.</p> | <p>Increased % with BP, LDL within guidelines, who had stopped smoking and with atrial fibrillation who were on oral anticoagulation in Part B compared with Part A.</p> <p>No randomisation to intervention and control group, so potential difference in unobserved baseline characteristics.</p> <p>Comparison was between two consecutive not simultaneous cohorts of patients so there may have been increased awareness of adherence to guidelines by patients and doctors in the second cohort.</p> <p>No blinding of follow up assessment.</p> |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|-----------------------------------|--|---|
| Lennon et al (2008). Ireland. | Randomised, controlled trial. N=48. Community dwelling, ischaemic stroke survivors. Participants were all at least 1 year post-stroke. Age 60.5 +/- years (control), 59 +/- 10.3 (intervention). 10 week programme of twice weekly, cycle ergometry, in pairs, plus two life skills sessions to address relaxation, stress management & life balance. Outcomes measured at week 1 and week 10. Cardiac risk score, HADS, Fasting lipid profiles, Frenchay activity index, resting blood pressure. | Improved cardiovascular fitness, reduced cardiac risk score, improvement in self-reported depression. Possible Hawthorne effect due to lack of attention equivalent control. No long term follow up Participants exercising in pairs so made very little use of group interactions and peer support. |
| Marsden et al (2010) Australia | Randomised, assessor blind, cross-over controlled trial. N= 25 stroke survivors, 17 carers. Community dwelling, chronic, stroke survivors and their carers. Age 70 +/- 9 years (intervention), 73.1 +/- 9.3 years (control). Group programme, once a week, for 7 weeks of self-management principles, education, physical activity and a 'healthy options morning tea' compared to usual care. Outcomes measured at baseline, post intervention and at week 21. | Small numbers. Trend to an improvement of 10% in Stroke Impact Scale between intervention and control groups. Most measures still above baseline at the final follow up but long term impact not known. |
| McAlister et al (2014) Canada | Prospective, randomised, controlled trial. N=279 TIA or ischaemic stroke with no, or slight, disability. Age 67.6 years. Control vs pharmacist case manager or nurse case manager, 6 x monthly follow up visits with medication adjustment, BP & lipid level monitoring, emphasis of medication and lifestyle adherence, communication with physician. Outcomes measured at baseline, 6 & 12 months. | Improvement in global vascular risk factors with either nurse or pharmacist case manager that persisted after active intervention. |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|--------------------------------|--|---|
| Prior et al (2011) Canada | Prospective, pre-post, cohort design. N=100. Post-acute TIA, or mild, non-disabling stroke, within 12 months (mean 11.5 weeks post event). Age 64.9 years. Comprehensive cardiac rehabilitation for 6 months | Significant improvements in aerobic capacity, cholesterol, waist circumference, BMI, body weight plus shift to non-smoking. |
| Wolfe et al (2010) UK | Pragmatic, cluster randomised trial. N= 523. Within 6 months of stroke. Usual care vs 'Stop stroke' intervention – identifying stroke survivors' risk factors for recurrence and giving evidence based management advice to GPs, patients and caregivers at 10 weeks, 5 months & 8 months post stroke. Outcomes measured at baseline & 1 year. Risk factor management – treatment with antihypertensive, antiplatelets and smoking cessation. | Loss to follow up of 88/274 (intervention), 66/249 (control). No improvement in risk factor management identified. |
| Sit et al, (2007) Hong Kong | Quasi-experimental design: N = 147 Chronic, minor stroke. Community based, group, stroke prevention, self-management programme including teaching, interactive tasks and peer support. Two hours, once a week, for 8 weeks Outcomes measured at Baseline, 1 week & 3 months after intervention. Stroke knowledge questionnaire, self-health monitoring questionnaire and self-report of health behaviours. | Improved knowledge & skills. Changing behaviours in the intervention group sustained at the three-month follow up. Possible Hawthorne effect due to lack of randomisation and different attention levels between the two groups. No long term follow up. Self-report of health behaviours subject to social desirability bias. No blinded assessment. |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|---------------------------------|--|---|
| Sol et al (2008) Netherlands | <p>Randomised, controlled trial. N=153</p> <p>Symptomatic vascular diseases (cerebrovascular, abdominal, coronary or peripheral)</p> <p>Usual care vs nursing care included promoting self-efficacy through individualised information about vascular risk factors, goal setting, monitoring and feedback plus medical treatment of vascular risk factors.</p> <p>Outcomes measured at baseline and 1 year.</p> <p>Self-reported self-efficacy questionnaire and vascular risk factors.</p> | <p>Statistically significant increase in self-efficacy towards healthy food choice and doing extra exercise.</p> <p>No change in vascular risk factors.</p> <p>Self-reported questionnaire subject to social desirability bias.</p> <p>No attention control so possible Hawthorne effect.</p> <p>No blinded assessment.</p> |
| Tang et al (2010) Canada | <p>Repeated measures design. N= 43.</p> <p>Mild to moderate stroke and able to walk more than 10 metres independently, with or without aids. 30 +/- 28 months post stroke. Age 65 +/- 12 years.</p> <p>Six month programme of once weekly, 30 – 60 minute session, of supervised, individually prescribed, aerobic & resistance exercise plus home exercise programme. 80% of exercise sessions were unsupervised. Education session 1 – 2 times per month.</p> <p>Outcomes measured at beginning and end of 3 month baseline pre intervention period and at 6 months i.e. immediately after intervention.</p> | <p>Feasible to include those with mild to moderate stroke in a cardiac rehabilitation programme, if adapted to accommodate disability, including higher staffing levels and alternative equipment.</p> <p>Statistically significant improvements in cardiorespiratory fitness measured in VO2 max.</p> <p>No control group. Possible Hawthorne effect.</p> <p>Low attrition and adverse event rates.</p> <p>93% programme completion.</p> |

| Author(s) / Country | Design, intervention & participants | Findings & comments |
|--|---|--|
| Tielemans et al (2015). Netherlands | <p>Multicentre, randomised, controlled trial. N= 113</p> <p>Chronic, stroke survivors, average 18 months post stroke, with at least two restrictions in participation.</p> <p>Age 57 +/- 9 years, 57 partners, age 59.2 +/- 8.3 years.</p> <p>10 week, group based, education intervention vs 10 week, group based 'Restore4stroke' group, rehabilitation professional-led. Self-management intervention 'Plan ahead!' aimed at proactive coping, for stroke survivors and carers. 6 x 2 hour sessions in first 6 weeks, then booster 2 hour session in 10th week.</p> <p>Proactive action planning, stroke-specific elements, partners treated as full participants with own goals.</p> <p>Outcomes measured at baseline, post intervention and at 3 and 9 months follow up. Utrecht Proactive Coping Competence scale, General self-efficacy scale, Stroke specific quality of life scale, HADS, Caregiver Strain Index.</p> | <p>Significantly increased partners' proactive coping.</p> <p>Trend towards improvement in partners' self-efficacy, stroke survivors, participation, and health related quality of life and mood.</p> <p>Partial attention control in place 4 x 1 hour sessions over 10 weeks compared with 7 x 2 hour sessions over 10 weeks.</p> |
| White et al (2013) Australia. | <p>Mixed methods study (quantitative pilot data & qualitative semi structured interviews). N=22. Community dwelling, chronic, stroke survivors.</p> <p>Age 65.8 +/- 11 years.</p> <p>Intervention: Masterstroke programme – 9 weeks, 2 x two hour sessions per week, comprising group exercise and education. Exercise included fitness, strength, mobility & balance.</p> <p>Education – secondary stroke prevention and chronic condition self-management support, included stroke risk factors, nutrition, diet, managing social isolation and depression. Goal setting.</p> <p>Outcomes measured at baseline, intervention end and 3 months later.</p> | <p>Statistically significant improvements in Stroke Knowledge, Timed up and go, salt intake and quality of life scores.</p> <p>Qualitative results also showed increased stroke knowledge, exercise tolerance, lifestyle modification and success of group programme.</p> <p>No long term follow up</p> |

Table 4: Published protocols for multi-factorial programmes

| Author(s) / Country | Design, intervention & participants |
|-------------------------------------|---|
| Lennon & Blake (2009). Ireland | ‘CRAFTS’ Randomised, controlled trial. TIA and stroke 10 week programme of twice weekly, supervised, aerobic exercise plus individually tailored brief intervention lifestyle counselling, in the form of a two hour didactic lecture, addressing modifiable risk factors for stroke and stress management. Individual brief smoking cessation counselling, exercise and dietary advice including information leaflets for those failing to meet the recommended guidelines. Follow up for one year |
| Mackay-Lyons et al (2010) Canada | A four-site, randomised, controlled trial Recruited within 90 days of TIA or non-disabling stroke Usual care vs 12 week, twice weekly, group programme of exercise (75 minutes) and once weekly education (90 minutes), lifestyle counselling session, home exercise programme, goal setting, positive reinforcement, adult learning strategies, use of a health passport to document goals, appointments and assessment information and monthly follow up telephone calls. Primary outcomes will be blood pressure, waist girth, lipid profile, fasting serum glucose and haemoglobin A1c. Secondary measures include aerobic fitness, lower extremity function, walking endurance, physical activity levels, fatigue levels, cognition, quality of sleep, tobacco use, health care utilisation, medication adherence, health related quality of life, health related goals and secondary vascular events. Outcomes will be measured at baseline, post-intervention, 6 and 12 months. |
| Rochette et al (2010) | Randomised, controlled trial, ‘mild’ stroke 6 month intervention of information, education and telephone support |
| Heron (2013) | Randomised, controlled trial Those within two weeks of TIA. Home based cardiac rehabilitation, based on the ‘Heart Manual’ |
| Thrift et al (2014) Australia | Cluster randomised, controlled trial Individualised management programme following discharge home from hospital after stroke; evidence based template for GP plus stroke risk factor management education & counselling by nurse. |
| Lord et al (2015) USA | Randomised, controlled trial Ethnically diverse patients with TIA or mild stroke in New York A patient-paced, community health worker led, culturally tailored intervention, with motivational video & workbook on risk knowledge, medication adherence & patient/physician communication. |
| Joubert et al (2015). Australia | Prospective, multicentre, randomised, controlled trial. Planned n= 1000 underway. Usual care vs ICARUSS (integrated care for the reduction of secondary stroke) |

2.4 Discussion

A number of multi-factorial, group programmes to support vascular risk factor modification, after TIA or stroke, have been investigated, and although there is some promising evidence in favour of this type of intervention, most of this is from small scale, randomised, controlled trials (e.g. Joubert et al, 2008) or pre-post intervention studies (Prior et al, 2011). There are a number of large scale, randomised, controlled trials underway to gather more robust data (see table 4). None of the completed studies or published protocols, identified in this systematic review of literature, have investigated a multifactorial programme, designed to reduce vascular risk, for all those with acute or sub-acute stroke (including those with or without residual deficits), and that also included all the components of; exercise, education or information provision, problem solving, goal setting and action planning plus professional, peer and carer support. In addition, none of these studies have considered the inter-relationship between secondary prevention and rehabilitation after stroke.

Investigating clinical guidelines, it is noticeable that rehabilitation and secondary prevention are considered completely separately; with separate guidelines being produced for rehabilitation in the UK (NICE, 2013) and America (Winstein et al, 2016), to those for managing stroke including secondary prevention (Intercollegiate stroke working party, 2012; Kernan et al, 2014). The most recent UK national clinical guidelines for stroke, published in 2012 (Intercollegiate stroke working party, 2012), have limited guidance on addressing the non-pharmacological aspects of secondary prevention after stroke; suggesting an individualised and comprehensive strategy, with the health system responsible for giving accurate advice and information, plus providing support for stroke survivors to make and maintain, a number of specified lifestyle changes. No information is given on how that support should be provided. There is a single paragraph, in the more recent American stroke rehabilitation guidelines (Winstein et al, 2016), stressing the importance of secondary prevention and signposting readers to the stroke guidelines (Kernan et al, 2014). These guidelines take a biomedical approach to the medication, and individual lifestyle behaviour changes, required to minimize vascular risk after stroke (Kernan et al, 2014). The

emphasis for implementation is on supporting adherence to guidelines, at population-based and hospital monitoring level (Kernan et al, 2014). Factors such as smoking, hypertension and obesity are all dealt with separately, with lifestyle modification recognised as a reasonable part of strategies, to manage these risk factors. There is limited emphasis on the stroke survivors themselves, other than counselling patients to follow a Mediterranean diet and stop smoking. Referring those, who are willing and able to initiate increased physical activity to a comprehensive, behaviourally orientated programme, is also deemed reasonable (Kernan et al, 2014). There is no mention of supporting stroke survivors to self-manage, or of multifactorial programmes.

The evidence base, for multi-factorial programme to reduce vascular risk, is growing rapidly. Mackay-Lyons et al (2013) reviewing multi-modal, non-pharmacological interventions, identified only one completed, small scale study (n=48) (Lennon et al, 2008), which met the inclusion criteria at that time, so did not draw any conclusions. A more recent review of organizational, educational or behavioural stroke service interventions, on modifiable risk factor control for stroke secondary prevention, included 26 studies and 8021 participants (Lager et al, 2014). The focus of this review was on service delivery and outcomes, in terms of physiological parameters, adherence to secondary prevention medications, secondary cardiovascular events and mortality. The majority of studies were deemed to be of reasonable quality; however, this review concluded that the studies that included organizational change only had limited impact; and those that included only educational or behavioural interventions, had no impact on modifiable risk factors after stroke. This review sits within the biomedical paradigm.

In contrast, the more recent systematic review of multimodal, secondary prevention, behavioural interventions for stroke and TIA (Lawrence et al, 2015) sits within the biopsychosocial paradigm. This review focused outcomes not only on physiological outcomes, incidence of vascular events and mortality, but also on

lifestyle behaviour change, psychosocial outcomes, such as anxiety and learning outcomes, such as knowledge of stroke lifestyle risk factors. The review included 20 RCTS, with a baseline of 6373 participants. Intervention duration was from a single session, to 12 months, and the majority of trials (n=16) compared the intervention against usual care. Despite some limitations in the methodological quality of included trials, plus a lack of theoretical underpinning in terms of behaviour change theory; this meta-analysis demonstrated the effectiveness of multimodal interventions after TIA and stroke in; reducing blood pressure, improving medication compliance and reducing anxiety. This review was only able to report on outcomes; not on processes, or mechanisms underpinning the effectiveness of the interventions.

A number of studies, which explore the views of stroke survivors and caregivers, in terms of secondary prevention, rehabilitation and life after stroke, help to identify some of the key challenges with existing service provision; and also some of the key processes needed, in the development of multifactorial, stroke secondary prevention and rehabilitation programmes. A recent meta-review of qualitative, systematic reviews, specifically exploring experiences of self-management support following a stroke (Pearce et al, 2015), included seven reviews, reporting 130 separate studies (Lamb, 2008; Lui, 2005; McKevitt, 2004; Murray et al, 2003; Peoples, 2011; Reed, 2012 and Salter, 2008). Key themes identified were; the devastating impact of the stroke on self-image; the need for psychological, emotional and self-management support throughout the stroke recovery process; the variable information needs and the importance of good communication with the health care team. Pearce et al (2015) also identified the possible benefits of goal-setting and action planning; in addition that social support could be provided by stroke survivor groups.

Many of the same themes were identified in a recent, qualitative synthesis of stroke survivors and caregivers experiences, with rehabilitation and life after stroke (Lou et al, 2016). This synthesis identified two key findings; firstly, the profound disruption to life and the need for both stroke survivors and caregivers

to engage in a process of rebuilding a post-stroke life and identity, in line with the life-thread model (Ellis-Hill et al, 2007). This process of rebuilding involved five key elements; autonomy, uncertainty, engagement, hope and social relations (Lou et al, 2016). Secondly the experience of rehabilitation was viewed as temperamental and unstable rather than progressive. This view was less likely if rehabilitation was sufficiently person-centred, with effective goal-setting and review. Although person-centred goal setting is a key tenet of the self-management ethos (De Silva, 2011), there is only weak evidence of the effectiveness of this approach in stroke rehabilitation (Rosewilliam et al, 2011). There is also limited adoption in practice, due to a number of barriers, including the health care system and professional cultures; plus limited time and resources (Rosewilliam et al, 2011).

Looking at some of the key challenges, in relation to secondary prevention in stroke, from the perspective of stroke survivors and carers, finds some common themes. Two recent studies looking at medication adherence in secondary prevention after stroke; Souter et al (2014) (n=30 stroke survivors) and Jamieson et al (2016) (n= 28 stroke survivors, 14 accompanying caregivers) both identified issues including; beliefs and lack of information about the stroke and the importance of the medication; practical difficulties in taking the medication; and the importance of the caregiver in providing information and giving practical support. Bushnell et al (2014) attempted to address these issues by providing an intervention they described as transition coaching for stroke. This intervention included personalised one-to-one education about risk factors and medications; problem solving in relation to side effects and medication access; and follow up calls checking for persistence and adherence. Overall medication persistence was found to be 80%; however, the study lacked a control arm, so this might be due to a Hawthorne effect. Adie and James (2010) using a randomised, controlled trial methodology and a similar individualised intervention, based on social cognitive theory and which included a focus on smoking, diet and exercise, in addition to discussion about medication use; found no improvement in blood pressure, though some improvement in statin use.

It is not only in terms of medication adherence that there are issues in secondary prevention for stroke survivors and caregivers. Allison et al (2008), in a study of 14 stroke survivors and 8 caregivers, found difficulties in understanding and recalling information, plus challenges in relation to health beliefs around stroke risk, and the difficulty of making lifestyle behaviour changes. Similar issues in relation to lifestyle risk factors were found by Lawrence et al (2010), in a focus group study involving 29 stroke survivors and 20 family members. These issues included; the challenges of conflicting and confusing advice and information; the impact of stroke impairments; access to appropriate resources and the influence of peers and family, both negatively and positively, on behaviour change.

A recent qualitative review and meta-aggregation (Lawrence et al, 2015), which aimed to understand both stroke survivor and family member perspectives of secondary prevention interventions, extracted data from five papers. These data were synthesised to produce three key findings; ‘feeling supported’, ‘acquiring knowledge’ and ‘gaining confidence’. Feeling supported came from; being part of a group with shared experiences; the support of expert and experienced health professionals; and the ongoing support of family members. Acquiring knowledge included; understanding the possible causes and impact of the stroke; the modifiable risk factors; and how and why lifestyle behaviour changes, could reduce the risk of further stroke. Gaining confidence was seen as resulting from; feeling encouraged; overcoming fears; and developing a positive attitude. In addition to identifying findings, this review was able to highlight some key processes that led to these findings. These processes included; peer and professional support; and tailored information provision, taking account of the individual’s current knowledge and readiness to learn. The recommendations from the review were; firstly that health professionals should consider implementing group-based secondary prevention interventions; secondly that those interventions should be person centred i.e. relevant and meaningful to the individual; and finally that stroke survivors and family members were more likely to comply with expert and experienced health professionals.

2.5 Conclusions

Reviewing the literature, there has been no investigation of a multi-factorial programme, designed to reduce vascular risk, for people early after stroke, including those with residual impairments. Theoretical modelling, and evidence to date, suggests that any intervention, designed to reduce the risk of recurrent stroke, should be multi-factorial; support adherence to medication; provide information and support; and include exercise. The qualitative studies reviewed suggest group based interventions are needed that incorporate individually tailored information, which takes account of an individual's impairments, current understanding and readiness to learn. In addition, the intervention should be underpinned by behaviour change theory, to facilitate health behaviour changes and ability to self-manage common, lifestyle related risk factors, such as hypertension and obesity. Qualitative studies suggest the need for both peer and expert professional support, to enhance positive influences on health behaviour change. Guidelines suggest an element of support, and information for caregivers and family members, provided in a group context, may also be a beneficial component of such a programme. Qualitative studies also reinforce the need to involve peers, caregivers and family members to provide peer support (Lawrence et al, 2015).

In the following chapter, the process of development of a multifactorial programme, designed to enable effective self-management, early after stroke, is described. The aim of this programme was to; support adherence to medication; provide information and social support; and promote health behaviour changes. Developing a model of practice, that supports those after stroke to make the changes likely to reduce vascular morbidity or mortality, would be a critical innovation in stroke care. The objectives for the development of such a programme would therefore be to: a) clearly describe the development and organisation of the programme; b) identify the outcomes of the programme; and c) evaluate the effectiveness of the programme. The journey towards considering these objectives is addressed in the subsequent chapters.

Chapter 3 Methodology and methods

3.1 Introduction

In this chapter, the methodology used for both the practice development project and the two phase research evaluation are justified, supported by critical evaluation of relevant literature. Outline methods, for both the practice development project and the primary research evaluation, are then discussed. Finally, the methods for the research study are presented, including discussion of the ethical issues, recruitment, inclusion and exclusion criteria, intervention, data collection and analysis process.

3.2 Practice development

Prior to starting the practice development project, it was important to understand the origins and underpinning philosophy of practice development. Practice development methodology in healthcare arose in the late twentieth century, as part of the move towards a more evidence based, and reflective, graduate healthcare workforce. Over recent years, practice development has become established and is regarded as a person centred approach, to developing existing practice and improving patient care. There are some variations in approach. McCormack et al, (2013) identify nine philosophical principles for practice development; including person-centred evidence based care; integration of inclusive, participative and collaborative evaluation approaches; plus taking an emancipatory viewpoint that people can be empowered to transform their own practice.

In contrast, the definition by Manley et al (2008, p9), emphasises that practice development is a facilitated, creative process, embedded in a learning culture and an organisational context.

*“Practice development is a continuous process of **developing person centred cultures**. It is enabled by facilitators who authentically engage with individuals and teams to blend personal qualities and creative imagination with practice skills and practice wisdom. The learning that occurs brings about transformations of individual and team practices. This is sustained by embedding both processes and outcomes in corporate strategy”.* Manley et al (2008, p9)

In addition, Manley et al (2008) argue that practice development requires the presence of **external** facilitation; whereas, McSherry and Warr (2008) acknowledge that those in practice development roles, including consultant nurses

and therapists, can facilitate practice development using their existing skills of; communication, collaboration, encouraging, enlightening, enabling, engaging and evaluating. In this doctoral practice development, the author and her nurse consultant colleague, acted as **internal** facilitators, and were responsible for both facilitating and implementing the practice development, in partnership with participants.

Methodologies, linked with practice development in health care, have evolved mainly within a nursing context (Titchen & Higgs, 2001); and consist not of a single specific intervention, but draw on a number of methods, that embody practice development principles, and which are also widely used in other forms of service and quality improvement (McCormack et al, 2013).

The primary purpose of practice development is to develop practice, with the development of knowledge, being a secondary, rather than a primary aim (McCormack et al, 2013). In addition, the knowledge gained from practice development, is usually regarded as transferable rather than generalizable, (Page & Hamer, 2002) due to the contextual nature of the understanding. Developing generalisable knowledge, about the practice development intervention, was identified as a key ethical issue by the author, who wanted to ensure parity for stroke survivors. The author was therefore initially considering a randomised, controlled trial, in order to develop generalisable knowledge from the practice development project.

It was clear that the planned practice development would have many of the characteristics of a complex intervention, including; individual tailoring of multiple interacting components; complex behaviours required by staff and participants; and a variety of outcomes (Craig et al, 2008). The Medical Research Council guidance on developing and evaluating complex interventions, suggest a number of processes, prior to a randomised, controlled trial. These are; identifying existing best evidence and appropriate theory; modelling process and outcomes; and testing them with a series of pilot studies, prior to a pilot evaluation phase to assess feasibility; then a full scale controlled experimental evaluation of the complex intervention, including economic evaluation (Craig et al, 2008).

Analysing the methods used in practice development, identified by McCormack et al (2013) and the elements of developing and evaluating a complex intervention, identified by Craig (2008); there are some commonalities, but there are also some clear differences; due to the person-centred ethos of practice development and the research focus of the complex intervention guidance. As this professional doctorate required both practice development and research; and as the planned practice development was to be based on self-management principles, which are also embedded in a person-centred ethos; the complex intervention guidance was used as an overall framework for this doctoral work, supported by methods commonly used in practice development (McCormack et al, 2013). Table 5 highlights which of the methods, that are underpinned by the philosophical principles of practice development, were used in this doctoral practice development.

Table 5: Methods used in practice development

| Practice development methods (McCormack et al, 2013, p7) | Used in this practice development? |
|---|---|
| Agreeing ethical processes | Yes |
| Analysing stakeholder roles and ways of engaging stakeholders | Partially |
| Being person centred | Yes |
| Clarifying the development focus | Yes |
| Clarifying values | Yes |
| Clarifying workplace culture | No |
| Collaborative working relationships | Yes |
| Continuous reflective learning | Yes |
| Developing a shared vision, | Yes |
| Developing critical intent | Yes |
| Developing participatory engagement | Yes |
| Developing a reward system | No |
| Evaluation | Yes |
| Facilitating transitions | No |
| Giving space for ideas to flourish | No |
| Good communication strategies, | Yes |
| Implementing processes for sharing and disseminating | Yes |
| High challenge and high support | No |
| Knowing 'self' and participants | Yes |

Table 6 outlines which of the elements of the complex intervention framework are addressed, where within this doctoral thesis, as there is recognition that the development and evaluation of a complex intervention may not follow a linear sequence (Craig et al, 2008). The aim was that the intervention would have the

potential, to reduce vascular risk, by improving the self-management ability of recent stroke survivors, in relation to multiple modifiable risk factors. In order to successfully reduce vascular risk after stroke, a multifactorial programme was required, that effectively supported the type of behaviour change required, to modify lifestyle risk factors in the real world, not just controlled research studies. By working closely with stroke survivors and caregivers in the development of the intervention, it was anticipated that a pragmatic, inclusive intervention would be developed, that was feasible in the real world, not just in a research setting, and that had good adherence and completion rates and was transferable to other settings.

Table 6: Development and evaluation of the ASPIRE programme, a complex intervention (based on Craig et al, 2008).

| Development | Comments |
|---|---|
| Identifying existing evidence | Presented in chapter 2 |
| Identifying and developing theory | Section 3.3 Further developed in chapter 5 |
| Modelling process and outcomes & testing them | Series of PDSA cycles in chapter 4 |
| Assessing feasibility | Some of the findings from modelling process and outcomes are preliminary data which could contribute to a future feasibility study. |
| Evaluation | |
| Assessing effectiveness | Intervention not tested with sufficient numbers to fully assess effectiveness. |
| Measuring outcomes | A range of outcome tools trialled alongside the intervention. |
| Understanding processes | Through reflections in chapter 5. |

3.3 Identifying and developing theory

Craig et al (2008) stress the importance of being aware of the relevant theory, rather than developing an intervention in a purely pragmatic or empirical way. A theory has been defined as a “coherent and non-contradictory set of statements, concepts or ideas that organises, predicts and explains phenomena, events and behaviour” (Eccles et al, 2005). Thus, understanding theories, and the concepts within those theories that bring about change, should be considered in the planning of an intervention, to enable that intervention to affect the planned outcome (Sirur et al, 2009). Some of the key theories underpinning self-

management and health behaviour change are; ‘the Health Belief Model’ (Rosenstock, 1988); ‘the Theory of Planned Behaviour’ (Ajzen & Fishbein, 1980); ‘Self-Efficacy Theory’ (Bandura, 1997); and the ‘Stages of Change (transtheoretical) model’ (Prochaska & Velicer, 1997).

The Health Belief Model (HBM) (Rosenstock, 1988), identifies four key co-dependent beliefs, that predict whether an individual will take action to promote or protect their health; their beliefs about susceptibility to a condition; their beliefs about the seriousness of that condition and its potential impact; their beliefs about what possible actions can be taken to reduce the likelihood or impact of that condition; and the belief that the benefits outweigh the barriers or costs of taking action. The HBM can therefore be used to understand, how beliefs about health, can affect the way a person behaves, in relation to their health. It is thought that education alone, to increase knowledge about preventative health measures, may not be the most effective strategy, since health beliefs such as self-efficacy may mediate the way someone behaves (Abraham & Sheeran, 2005). The HBM is well established, and a recent systematic review has demonstrated improved adherence to behaviour change, in those interventions based on the HBM (Jones et al, 2013). The HBM is thought to be less successful in relation to complex behaviours, that are influenced by society, such as smoking (Nutbeam & Harris, 2004), due to lack of consideration of the context in which the individual lives, and how their significant others may influence health beliefs. The Theory of Planned Behaviour (Ajzen & Fishbein, 1980), builds on the concepts in the HBM, to include consideration of how social pressures, and the perceived desirability of a particular behaviour, will influence behaviour change.

Irrespective of beliefs about, and perceived desirability of a behaviour, health behaviour change is a process, that will only happen, when the time is right for an individual (Tomkins & Collins, 2006). The transtheoretical (stages of change) model identifies six key stages to the process of health behaviour change; from **precontemplation** i.e. having no plans to or not even considering change; **contemplation** i.e. considering or weighing up whether or not to change; through to **preparation** when an individual commits to change; **action** when the change is actually initiated; moving to **maintenance** when the behaviour change is

sustained and finishing with **termination** after prolonged behaviour change (Prochaska & Velicer, 1997). A Stages of Change questionnaire, based on the transtheoretical model, was used in a study by Garner & Page (2005). This study examined the readiness, of 178 community-dwelling stroke survivors to start an exercise programme and their current exercise patterns; and found that many months after their strokes; nearly 70% of individuals were still in the precontemplation or contemplation phase. Only 5.6% were in the action; and 15.2% in the maintenance phases i.e. exercising regularly. This suggests that understanding an individuals' readiness to change, is important.

The process is not always linear as an individual may return to a previous stage in the process (Rutter & Quine, 2002). Critics of the transtheoretical model argue that this is because the model fails to take account of motivational factors (West, 2005); such as associative learning, and reward and punishment, that can lead to unhealthy behaviours such as smoking becoming habitual (Etter & Sutton, 2002). It is therefore important to understand an individual's motivations underpinning unhealthy behaviours.

No matter how strong the intention to change, a further factor influencing whether behaviour does change, is the individual's self-efficacy towards that specific behaviour. Self-efficacy is a psychological concept, derived from Social Cognitive Theory, that explores how a person's beliefs in their capabilities influences the outcomes they are able to achieve (Bandura, 1997); i.e. self-efficacy is the knowledge, skills and confidence an individual has, in relation to a specific task. Self-efficacy as a concept, has commonly been used in self-management of other long term conditions, and has more recently been used in stroke. Higher levels of self-efficacy after stroke have been shown to be predictive of; improved quality of life; less depression (Robinson-Smith et al, 2000); more independence in functional activities; and reduced falls (Hellstrom et al, 2003). Bandura (1997) identified four key influences, on a person's beliefs about their ability to achieve a particular task or behaviour; experience of previous success (task mastery), vicarious experience, verbal and social persuasion plus physiological state; the somatosensations and emotions experienced when attempting to carry out that task or behaviour. This

theory, informs the development of strategies, which could increase an individual's identified self-efficacy, towards a specific health behaviour change.

Critical evaluation of the theory, underpinning self-management, highlights a number of key concepts, which should be used in developing a self-management intervention. These concepts can be grouped into two categories: Identifying an individual's beliefs, social context, motivations, self-efficacy and readiness to change in health behaviour; and supporting individuals to manage those changes in health behaviours. By understanding an individual's beliefs, motivations, self-efficacy, social context and readiness to change, then relevant information can be presented, in the right way for that individual, at the right time. Understanding an individual means that strategies can be developed, to build self-efficacy in relation to positive health behaviour change, that is important to that individual, at that time, depending on their goals. This may be, for instance, increased physical activity to lose weight for an upcoming important occasion, or smoking cessation for financial gain.

Identifying and understanding an individual's beliefs, social context, motivations, self-efficacy and readiness to change, could be done through an in-depth interview. Supporting individuals, to manage those changes in health behaviours, could also start during that interview, and the individual's belief strengths and evaluation of outcomes could be influenced (Sutton, 2002). Motivational interviewing (Miller & Rollnick, 2002) is one approach that could be used, to explore and resolve ambivalence, towards behaviour change (Markland et al, 2005) and has been shown to be successful, in supporting behaviour change after stroke (Green et al, 2007; Byers et al, 2010). The four general principles of motivational interviewing; (expressing empathy, developing discrepancy, rolling with resistance and eliciting change talk) enable exploration of an individual's beliefs; supports them to evaluate the benefits and barriers to change; supports his/her self-efficacy; facilitates progress through the stages of change and identifies implementation intentions (change talk) (Markland et al, 2005). The individual can also be encouraged to formulate implementation intentions, (the

‘how’, ‘when’ and ‘where’ of behaviour change), that have been shown to increase the translation of intentions into actions (Rutter & Quine, 2002).

Influencing self-efficacy could also support individuals, to manage those changes in health behaviours. Supporting individuals to set and meet small achievable goals, with appropriate monitoring, plus support for problem solving and feedback, would all enhance task mastery. Vicarious experience could be gained by; providing opportunities for stroke survivors to learn from other stroke survivors, either directly as fellow participants in a group intervention; through vignettes in written materials; or through examples given by healthcare staff and volunteers. Verbal and social persuasion could be provided through; interactive group discussion with, or information from, other stroke survivors, including written information and videos; or through informed caregivers and family members. Interventions could produce positive emotional and physiological feedback through; ensuring a relaxed, supportive environment; attainable goals; and the locus of control with the stroke survivor.

Many of these theoretical principles were encompassed in the development of the Chronic Disease Self-Management course (CDSM), a generic group education course for chronic conditions (Lorig & Holman, 2003). This course emphasises the acquisition of five core skills, for an individual with a long term condition; problem solving skills and goal setting; the ability to make decisions about managing with the condition day to day, based on sound knowledge and information about that condition; finding and using suitable resources and support; working in partnership with healthcare providers; and taking action to master new skills and change behaviour (Lorig & Holman, 2003).

When trialled in a stroke context; however, the CDSM showed limited improvement in stroke specific quality of life, no impact on mood or self-efficacy (Kendal et al, 2007) and had lower adherence rates than a stroke specific self-management programme (Cadilhac et al, 2011). Although there were some methodological issues with these studies (see chapter 2), the limited benefits seen may also be that the theories used were not relevant to the specific health context (Rutter & Quine, 2002). The theories assume the participant can use cognitive

processes such as; foresight, planning, decision making plus goal directed and self-regulating behaviours. This may be an issue in those whose stroke affects their frontal lobe and some of their higher level functions.

Recent national guidance, on interventions to support individual behaviour change, in relation to modifiable vascular risk factors, identified three behaviour change techniques that were likely to achieve success; planning and goals, feedback and monitoring, and social support (NICE, 2014): all of which are aligned with techniques in CDSM programme. When modelling process and outcomes, and testing them in a series of pilot studies, consideration was given to the relevance of the theories, to the specific local context, of a self-management intervention, to reduce vascular risk after stroke. These considerations are discussed in the next section.

3.4 Considerations for developing the practice development intervention

Prior to developing the intervention, a number of issues needed to be considered, in terms of process and outcomes including; type of intervention, location, resources and funding, referral processes, staffing and outcome tools to be used.

The aim of the planned intervention was that, it would have the potential, to reduce vascular risk, by enhancing the self-management ability, of recent stroke survivors, in relation to multiple, modifiable risk factors. A strong influence on the development of that intervention, was working in a hospital with only, on average, 300 admissions with acute stroke each year. Developing an intervention which could be accessed by all stroke survivors, would be the most effective use of resources; and equitable, as it could be accessed by those with or without residual deficits. As it was unclear from the literature what factors would influence attendance, it was decided that every inpatient discharged directly home from the acute stroke unit, rather than being transferred to the stroke rehabilitation hospital, would be invited to participate in the programme, irrespective of residual physical, cognitive or communication deficits.

It was hypothesised that a face to face intervention, was most likely to support those with cognitive and communication deficits, as understanding could be checked, and alternative modes and formats of communication used. The author had previously undertaken communication skills training, provided by 'Connect', the communication disability network, and planned to employ these skills within the intervention. It was also hypothesised, that a group based intervention, would be the most effective use of resources. The programme was developed, using a rolling recruitment format, rather than a cohort group, to enable participants to access it, immediately after discharge, without a waiting list, and also to enable a phased end to the programme as suggested by Harrington et al (2010).

In summary, the initial intervention was planned to be a rolling recruitment, group based, face to face, self-management programme; supported by an individual, in-depth interview; included both stroke survivors and caregivers; and also included an exercise component. As many developments in stroke have acronyms, and in order to quickly describe a complex intervention, the programme was initially named, the Life after Stroke Yeovil (L.A.S. Yeovil) programme.

In terms of location, a non-health based venue would be more conducive to a person-centred, rather than health professional led approach; however, no free, accessible venue was found, other than a rehabilitation room in the day hospital. As no new funding was available, a pragmatic agreement was reached with both employers and the commissioners, to deliver the programme, as an outpatient clinic, under the existing block contract. It has been argued that rehabilitation professionals and family caregivers are both well placed, to play a key role in programmes, designed to improve control of risk factors in stroke. Family caregivers are able to give support and reinforce advice about lifestyle risk factor management, and rehabilitation professionals are well used to problem solving, and goal setting, with a wide range of individuals (Ellis & Breland, 2014). Therefore, at their initial invitation to attend, stroke survivors were informed that they were welcome to bring someone, such as a close family member or friend, with them. The programme was initially run by the author and a stroke nurse consultant colleague.

To ensure a smooth referral process, the initial intervention was developed, following close discussions with the stroke team, so they were aware of the programme from the start. All the wider stroke team including; stroke coordinators, assistants, nursing, rehabilitation, medical and allied health professionals were informed about the programme through; the county wide stroke strategy group and the inpatient stroke working group. Information about the programme, including referral forms, is also available on the stroke pages of the hospital trust intranet. In addition, a clinician information sheet about the intervention was sent to General Practitioners, along with stroke unit discharge letters.

It was recognised that, appropriate outcome tools would be needed, in order to evaluate the effectiveness of the intervention. Identifying outcome tools that might provide appropriate feedback to individual participants, as well as providing outcomes of the effectiveness of the intervention was challenging, as it was difficult to determine whether there were likely to be any common outcomes, due to the heterogeneity of the participants. With the aim of the programme being secondary prevention and supporting the ability to self-manage after stroke, the obvious, though rather long-term measure, for evaluating the effectiveness of the programme, would be reduction in recurrence of stroke or other cardiovascular event. Service data collection processes at the time were insufficiently robust to provide this information in a reliable way. In addition, the numbers likely to be required might take several years in such a small organisation. It was known at the time, that after TIA, systolic blood pressure is predictive of further vascular events, such as stroke and myocardial infarction (Rothwell et al, 2005); however, the predictive value of blood pressure measurements after stroke was less certain.

There was evidence to suggest that, by including exercise circuits, there could be changes in function (Ada et al, 2006; Duncan et al, 2003; Katz-Leurer et al, 2003; Mead et al, 2007); however, finding outcome tools to assess function, that could be used with all participants, could be difficult due to heterogeneity; leading to floor effects with some tools, such as the 9 hole peg test (Mathiowetz et al, 1985), walk speed tests (Kosak & Smith, 2005) and Action Research Arm Test (Lyle,

1981); and ceiling effects, or insufficient sensitivity to detect a difference, with other measures such as the Barthel Index (Mahoney & Barthel, 1965) and Functional Independence Measure (Turner-Stokes et al, 1999).

It was also thought likely that there could be improvements in physical fitness in participants; however, with no access to technological monitoring equipment, to measure parameters such as oxygen consumption, and no budget for monitoring blood lipid or glucose levels; the only available options were monitoring weight and blood pressure, as proxy measures of changes in physiological function. It was difficult to anticipate how many would demonstrate change, as people may start the programme with blood pressure already within the target range.

It was considered that an alternative approach, to trying to find a common outcome tool, might be to use multiple outcome tools, including psychological and behavioural tools. At the time, previous studies had measured changes in self-efficacy, quality of life and mood (Kendall et al, 2007) plus knowledge, skills and health behaviours (Sit et al, 2007). The author felt that using this number and range of outcome tools, might cause challenges with recruitment and might also be considered unethical, by overburdening people already dealing with the life-changing consequences of having had a stroke. Finding the most appropriate outcome tool to use, with this specific intervention, was clearly to be a priority for the research phase of the development of this complex intervention. This will be discussed in the following section.

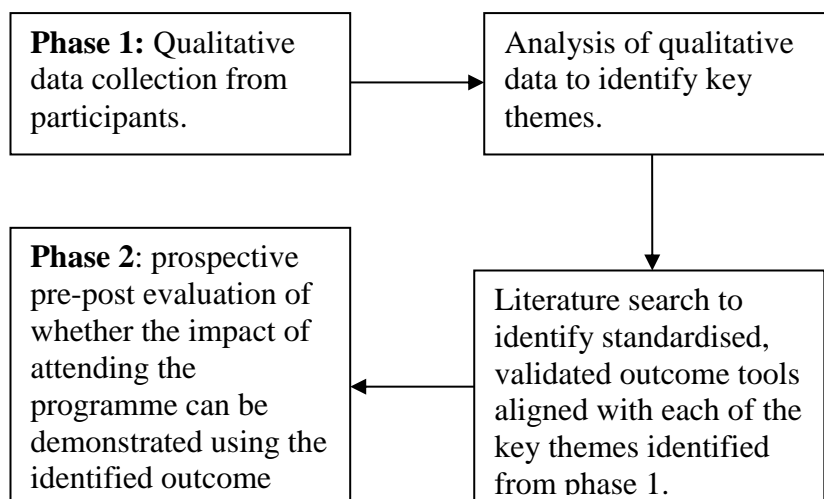
3.5 Choice of research methodology

The full development and evaluation of a complex intervention is beyond the scope of a doctoral programme; however, it was felt that complex intervention methodology would provide a framework, for developing generalisable knowledge from the practice development project, and for further research. It was also anticipated that the effectiveness of the intervention could not be fully evaluated as part of a doctoral programme. The doctoral programme could contribute information necessary for planning future research, such as identifying appropriate outcome tools, and developing an understanding of the processes

contributing to the intervention. This guided the choice of research methodology to be used. In addition, as it is now well recognised that a critical factor for success is the involvement of patients in the design process (INVOLVE, 2009), the author sought the views of participants. This approach is also aligned with the practice development principle, of using evaluation processes that are inclusive, participative and collaborative (McCormack et al, 2013)

The challenges, in identifying appropriate outcome tools to use for this intervention, led the author to decide the best way to find out would be to ask participants, of the intervention themselves, for their views on what they felt the outcomes were for them. A number of different qualitative approaches could have been used, in this first qualitative phase, of a mixed methods study, to answer the question “What in the view of participants are the outcomes of attending the intervention?” Analysing these data, might then give an indication of what could be captured, using standardised validated assessment tools. These tools could then be tested for feasibility, responsiveness and sensitivity on intervention participants. An exploratory, sequential, mixed methods, study design (Creswell & Plano Clark, 2007) was chosen, in order to place the service users (stroke survivors and carers), firmly at the centre of the research, with an initial qualitative phase, supporting the development of a quantitative phase. The study design is summarised in figure 1.

Figure 1: Mixed methods study



Qualitative phase 1

A phenomenological approach, although allowing exploration of the experience of the intervention, would have been likely to lead to a rich description of individuals' experiences, rather than an understanding of the processes and perceived outcomes from attending the programme, so would not therefore answer the research question. In contrast, a grounded theory approach for analysing the data, should allow the views of participants to surface rather than being imposed by the researcher. Grounded theory's approach to understanding individuals' experiences, actions and behaviours, from their own perspectives, in a specific context (Holloway & Wheeler, 2002) should help the author understand participants' views, of the outcomes from the ASPIRE programme, whilst recognising the heterogeneity of participants.

The grounded theory approach has within it a number of schools of thought. Glaser (1978, 1998, 2001 & 2005) despite advocating creativity, and the need to allow theory to emerge from the data, is prescriptive; describing the role of the researcher being to analyse 'the data', with little recognition of the contribution of the participant, or the interaction between researcher and participant, during the collection of data through an interview (Kvale, 1996). Having already worked in the field for some time, it would be difficult for to be able to approach, either the data collection or the analysis, with neutral open-mindedness (Glaser, 1978; 1998).

In contrast, Strauss & Corbin (1998) suggested that the interplay between the two roles might enhance the analysis of the data, as long as the author remained consciously self-aware of the tendency towards bias. Even more reassuring was the view of Charmaz (2006), who acknowledged the contribution of both the researcher and the participants, in the shared experience of data collection, and interpretation and construction of the data analysis. In addition, Strauss & Corbin (1998) and Charmaz (2006), provide a general guide of characteristics required (see table 7), a toolkit of analytical tools and suggestions for researchers to use creatively and flexibly.

Another feature viewed as fundamental to a grounded theory study analysis, is to be completely abstract of people, time or place, in order to transcend to the timeless immortality of an abstract theory, or integrated hypotheses and concepts that could be applied more widely Glaser (2001). Glaser himself acknowledged the challenges, for grounded theorists, of moving from the stage of developing categories grounded in the data, to the stage of developing theory and published a monograph to support researchers through that process (Glaser, 1978). Charmaz (2006) also stresses the importance of developing theory, in a grounded theory study; however, in contrast to Glaser (2001), Charmaz (2006) argues that the theorising itself is important; that there is huge variability in what constitutes 'theory'; and that the researcher, and the context of the research shape the theory developed.

Table 7: Characteristics of a grounded theorist (Strauss & Corbin, 1998, p7)

- The ability to step back and critically analyse situations
- The ability to recognise the tendency toward bias
- The ability to think abstractly
- The ability to be flexible and open to helpful criticism
- Sensitivity to the words and actions of respondents
- A sense of absorption and devotion to the work process

Overall, this study was more suited to an approach based on Charmaz's (2006) reflexivist; constructivist grounded theory rather than the more objectivist Glaserian grounded theory methodology. Full grounded theory is the development of a theory or model, by testing out and exploring aspects of the theory, and gaps in understanding the theory, so that the model can be applied to other contexts, thereby strengthening the use of it. The intention of this phase of the study was to gain specific understanding, of this particular situation, in order to inform a literature search, to identify validated tools to use. Therefore, grounded theory principles were used to guide the approach, rather than carrying out a full grounded theory study. The grounded theory principles used were that: 1) Interviews and their analysis informed successive interviews; 2) analysis started from the data, with no attempt to impose any outside assumptions or frameworks;

and 3) a reflexive approach was used to recognise when this may have occurred, and take this into account during the analysis.

Having discussed the qualitative approach used, consideration is now given to the data collection methods used. Interviews would give the richness of data needed including information gathering, opinion seeking, negotiations and influencing (Kvale, 1996). Semi structured interviews, although time-intensive, would also allow those with some cognitive and communication difficulties (van der Gaag et al, 2005) to participate in the research, which was important due to the inclusive approach planned. Interviews only with past participants would not; however, consider the views of those who chose not to or could not attend the intervention.

In addition, interviewing those who were offered but declined a referral to the intervention, might be unethical, as those declining might do so because of; comorbidities, carer stress, transport or financial difficulties. Furthermore, these individuals would have no experience of the intervention, so would be unable to help answer the research question. An alternative to interviews could have been a focus group. Focus groups have been used successfully in stroke survivors, including those with communication impairments (Nordehn et al, 2006), though use group dynamics to generate qualitative data (Gill et al, 2008). A focus group risks losing the variety of possible views, due to social desirability effects, or participants being unwilling to disclose sensitive issues in front of relative strangers (Gill et al, 2008). A written questionnaire was also rejected, due to the time-consuming nature for the participant, and the likelihood of getting responses that were superficial or missed the point (Hicks, 2009); plus ran the risk of excluding those, for whom reading or writing was difficult, due to stroke deficits.

The author having the dual roles of clinician and researcher, could pose both an ethical issue, in terms of the principle of autonomy (Holloway & Walker, 2000), and also a risk to the rigorousness of the research process. Those approached to take part in the research, may feel an obligation to participate, and those interviewed may not be completely frank, and either censor, or bias their

comments, through either a sense of loyalty (Holloway & Walker, 2000), or due to an unequal power relationship (Charmaz, 2006, p27). These risks would be minimised, by directly addressing this issue, in the participant information sheet and by only approaching those, who had already completed the intervention.

Quantitative phase 2

Once the key areas of impact of attending the 'ASPIRE' programme had been identified in phase 1 of the study, phase 2 sought to evaluate; a) Whether those key areas of impact lead to outcomes; and b) Whether currently existing, standardised, validated tools were able to assess those outcomes. Due to the heterogeneity of participants in the ASPIRE programme, finding a single standardised tool that captured all of the elements, identified in the interviews, proved impossible. It was therefore decided, to try and identify a selection of outcome tools from the literature, aligned to the main areas of impact identified in phase one.

Once tools aligned to the findings from phase one had been identified, they were tested in a prospective, pre-post evaluation, with a new cohort of participants. As an exploratory study, designed to test out the usability of the outcome tools, rather than the effectiveness of the intervention, participants were not randomised. The disadvantage of this methodology, is that without a control group, any significant changes in the outcome measures used (dependent variable), could not be ascribed to attendance at the intervention (i.e. the independent variable), and could be due to some other reason e.g. increased time since stroke. There was also a risk that, due to the heterogeneity of participants, the measures identified through interviewing one cohort might not be applicable to a further cohort; in which case no change would be found in the outcome tools chosen. To minimise this risk, it was planned to test the tools on a cohort of 20 stroke survivor participants. This figure was chosen, as a similar number to the size of the stroke survivor cohort interviewed in phase 1, so likely to show a similar degree of heterogeneity. Having discussed the implementation and methodological issues, for both the practice development and research study, the methods used for the practice development and research, will be discussed below.

3.6 Practice development method

McSherry and Warr (2008) stress the need to use assessment tools and techniques, to support and evaluate innovation within practice development. One well established and commonly used healthcare improvement tool, used to support and evaluate innovation, is Plan-Do-Study-Act (PDSA) cycles (Taylor et al, 2013; Leis and Shojanian, 2016). Each PDSA cycle allows small scale testing of change, in a real work setting. In each ‘Plan’ phase, objectives are identified, predictions about the outcome made and data collection planned. In each ‘Do’ phase, the plan is implemented, data is collected and issues and observations made. In each ‘Study’ phase, the data is analysed and compared to the predicted outcomes. Finally in each ‘Act’ phase, the information gained is used to decide whether to implement the changes and what the next ‘Plan’ phase should be. Table 8 identifies each of the PDSA cycles in this doctoral programme.

Table 8: PDSA cycles

| PDSA cycle | Timescale | Study component of cycle | Comments |
|------------|--------------------------|--|----------------------------|
| First | Autumn 2006 – April 2007 | Initial informal evaluation, focus group with participants. | ‘Life after stroke group’ |
| Second | April to October 2007 | Formal audit evaluation | Programme now named ASPIRE |
| Third | 2008-2009 | Phase 1 research data collection (patients & caregivers), transcription & analysis | |
| Fourth | 2009-2010 | Phase 1 research data collection (staff and volunteers), transcription & analysis. | |
| Fifth | 2010 – 2012 | Phase 2 research data collection & analysis | |

Each of the ‘Do’ phases of the multiple PDSA cycles for this practice development, were informed by notes and reflections from the author’s ‘praclog’, and ‘doclog’, plus formal evaluation of the practice development using either audit or research as illustrated in table 8. At the start of the practice development, it was anticipated, that the research phases would follow, and be separate from the practice development phase; however, the data from the research strongly influenced the ongoing practice development. Changes made to the practice

development intervention were initially made by the author, following discussion with the author's nurse consultant colleague, and over time included the growing group of staff and volunteers involved in delivering the intervention. The key changes made in each PDSA cycle, and the specifics of how those decisions were made, are discussed in chapter 4.

3.7 Phase 1 Research method - qualitative interviews

The objectives of phase 1 of the mixed methods study were to; *describe the key areas of impact of attending the ASPIRE programme, as identified by participants, using interviews.*

3.8 Ethics

An application for both phases of the study was submitted to the local NHS Research and Ethics committee, for ethical approval of the study, in February 2008; the author attended for interview in March 2008, and gained ethical approval by chairs action following minor amendments at the end of May 2008 (see appendix 1). Ethics approval was obtained prior to approaching potential participants. Formal approval was also gained from the university overseeing the doctoral programme, and the author's employing NHS organisation, in order to comply with research governance guidelines. As part of the ethics application, a risk assessment was carried out that addressed issues, including lone working.

The key risks and benefits of participating in the research study were clearly identified in the participant information sheet (see appendix 2). It was recognised, that participants may have found it upsetting to discuss the stroke event and its immediate aftermath, or to discuss their current abilities or life compared with those prior to the stroke. Reassurance, support and sympathetic listening were provided immediately by an experienced competent practitioner familiar to them (the researcher), and a telephone contact number for further support given if needed. The usual referral mechanisms would have been used, if a participant had developed extreme distress, though this did not arise. The main benefit, for those taking part in the study, was from someone taking a particular interest in and listening to them.

Informed written consent was sought, and gained, before any participation in this study (see appendix 3). If the author, as chief investigator, had any doubt about a potential participant's ability to give informed consent, due to communication difficulties, then the opinion of the participant's speech and language therapist would have been sought. Similarly, if the author as chief investigator, had any doubt about a potential participant's ability to give informed consent due to cognitive difficulties, then a Mini Mental State Examination score of >24/30 would have been used for inclusion. Neither of these situations arose, as those agreeing to participate in the research project, had adequate communication and cognitive abilities. The data protection act was taken into account, in relation to the storage of data for the research project. To ensure confidentiality, all files and memory sticks were password protected, not stored on a shared computer and all data was anonymised. Audio-tapes, transcripts and all other data were stored in a locked filing cabinet, within a locked office on NHS property. Participants' general practitioners were informed of the participation of their patient in the study.

3.9 Recruitment

As it was not known what influenced the outcomes from attending the ASPIRE programme, purposive sampling was not used; instead potential participants were contacted in chronological order of attendance. The inclusion and exclusion criteria for participation in this phase of the study are identified in table 9. As can be seen from the inclusion criteria, all potential participants had finished attending the ASPIRE programme, so were no longer seeing the author in her clinical capacity. To distinguish the research project from any on-going clinical care, potential participants were initially contacted by post with a letter and participant information sheet (appendix 9), sent from the author's university address, inviting them to participate in the study.

Potential participants were given two weeks, from receipt of the letter inviting them to participate in the research project, before a reminder was sent out. Those not responding, within 1 month of the original letter, were assumed to decline participation in the study. Those responding to the invitation were sent a consent form, along with a stamped addressed envelope. Once the signed consent form

was returned, the person was contacted by telephone, and an interview arranged at a time and venue convenient to the participant, most often their own home.

Table 9: Inclusion and exclusion criteria

| Inclusion criteria: | Exclusion criteria |
|---|--|
| Adult stroke survivors (diagnosed either clinically or medically and documented in their medical notes or referral letter) and their informal carers (as defined by the stroke survivor). | Unable to give informed consent. |
| All those who were able to give informed consent for themselves and to participate in a taped semi structured interview. | Unable to participate in an audio-taped semi structured interview due to insufficient language and / or cognitive abilities. |
| All those who had participated in at least one session of the ASPIRE programme, starting since November 1 st 2007 to avoid overburdening those who had already participated in a previous audit or focus group during the initial development phase. | Comorbidities that prevented full participation in ASPIRE i.e. the exercise session and also the information session. |
| First or recurrent stroke; ischaemic or haemorrhagic stroke. | Aged less than 18 years at time of stroke. |

Although a likely number of interviews had been identified, for ethical approval purposes (n= 20 stroke survivors, n=10 caregivers), this could not be accurately estimated, as it was planned to stop data collection, once additional interviews did not bring any new material to the analysis (i.e. 'theoretical saturation' was reached). At the time at which this point had been reached, the author realised that all the first 8 stroke survivors interviewed were men, and all of the first 6 caregivers interviewed were women. Purposive sampling (Hicks, 2009) was therefore used, to select the remaining potential participants invited to take part in the study, to ensure that views were sought from people who could be expected to hold a different perspective due to their gender. It was also ensured that the participants varied in age, and a range of social circumstances (such as living alone vs living with others; working vs retired / unemployed; living in an urban vs rural setting), which may be expected to affect their experience of attending ASPIRE. Those interviewed were representative of ASPIRE participants, though not of the stroke population as a whole, due to the over-representation of younger males.

3.10 Data Collection

Data collection for phase 1 of the study, consisted of audio-taped semi structured interviews with previous ASPIRE participants; stroke survivors and caregivers, carried out by the author. In addition, the characteristics of the ASPIRE participants in terms of age, gender and residual impairments from stroke at the time of attendance at ASPIRE, were identified through interview and checked against their clinical record. This allows the reader to understand the impact of the ASPIRE programme, in relation to the characteristics of the cohort, and also enables comparisons to be made with other interventions.

Perceptions of the impact of the stroke, and of the ASPIRE programme, were sought by interviewing stroke survivors and their caregivers. All except one person, who was interviewed at the hospital, chose to be interviewed in their own home. Interviews lasted from about 30 minutes to nearly two hours. The interviews were used to gather both quantitative information, such as the participant's length of stay in hospital, and qualitative information, such as how participants felt attending the ASPIRE programme had impacted upon them (Wengraf, 2001). The specific areas covered can be seen in table 10 and 11 below. This style of interview, although time intensive, allowed the participation of those with communication difficulties (van der Gaag et al, 2005) and generated a number of perspectives.

Interviews took place, in a private place of the participant's choosing, which in nearly every case was the stroke survivor / carer's own home. One person chose to be interviewed at the hospital, and one carer met the author, in the car park of her workplace, at lunch time. Prior to each interview, and after any immediate introductions that were needed, such as to other family members or pets, the author enquired after the health and wellbeing of the participants to put them at their ease. The interview took place in a room chosen by the interviewee, as a place likely to be free of interruptions, and with the author positioned so that eye contact could be maintained, and non-verbal prompts given to encourage the flow of the interview. Prior to the interview, it was checked that the interviewee had read, and understood, the participant information sheet and answered any questions they had, before they signed the consent form and indicated that they

were happy for the interview to be recorded. The semi-structured interviews were then audio recorded, using a tape recorder and microphone or a digital voice recorder. The recording equipment was then placed so that it could pick up both voices without being obtrusive.

Semi-structured interviews provided the opportunity for an in-depth exploration of interviewee's individual perspectives, using an open-ended line of questioning (Britten, 1995); based on an initial interview schedule and supplemented by prompts to encourage further discussion. Table 10 outlines the initial interview schedule for stroke survivors and Table 11 the initial interview schedule for caregivers as originally planned and submitted to the ethics committee. The main research question highlighted in bold was **“What impact do you think the ASPIRE programme had on you?”** The intention of the other questions was to relax the interviewee, develop rapport and to seek additional information about the interviewee's individual previous and current situation, in order to understand more about the context for the interviewee, and be able to ask appropriate personalised additional questions.

Throughout each interview, questions were asked in an open, non-directive way, with non-verbal cues and single words of encouragement, e.g. 'yes' to keep the flow of the interview. Gentle probes were used, such as, 'Is there anything else', and additional questions asked, to seek clarification, or their previous answers paraphrased, to check understanding of what had been said. Although Strauss & Corbin (1998) suggest that there is no need to tape interviews, just make notes, the author found it impossible to trust either the approach, or her memory sufficiently and wanted to be able to maintain appropriate levels of eye contact during the interview. The author also found her interview technique improved by listening to and reflecting on the audio recordings of previous interviews. At the end of each interview, the author checked if the interviewee had anything to add, before reminding them a copy of the transcript and a stamped addressed envelope would be sent to them, so that they could add or amend anything they wished, before returning it. Immediately after each interview, the author made field notes in her research diary ('doclog') about the situation in which the interview took place, how the person seemed and initial thoughts about key issues that emerged from

that interview, plus ideas that could be explored further in future interviews. Information on characteristics of the ASPIRE participants, in terms of age, gender and home situation, were taken from medical notes, so as not to detract from the main purpose of the interview.

Table 10: Initial interview schedule for stroke survivors

| |
|---|
| First of all can you tell me something about what life was like for you before you had your stroke? |
| Can you tell me something about your understanding of what caused your stroke? |
| And do you remember when you first came home, how were you then? |
| And what do you remember about the ASPIRE programme? |
| So what impact do you think the ASPIRE programme had on you? |
| So what would you change about the ASPIRE programme? |
| So now, how confident are you that you are doing what you can to reduce the risk of another stroke? |
| And how are things for you now? |
| I've asked all the things I wanted to ask, is there anything else you want to say? |

Table 11: Initial interview schedule for caregivers

| |
|---|
| Can you tell me what life was like for you before X's stroke? |
| And can you tell me what happened when (s)he had his / her stroke? |
| And what were things like when (s)he first came home from hospital? |
| So when was the ASPIRE programme first mentioned? |
| So what impact do you think the ASPIRE programme had on you? |
| So what would you change about the ASPIRE programme? |
| So how are things for you now? |

3.11 Analysis

The interviews were transcribed verbatim, as soon as possible, and the transcript checked against the recording for accuracy and to ensure reliability of interpretation. To increase credibility, transcripts were then sent out to interviewees, along with a stamped addressed envelope, and interviewees asked to check the transcript, to see if there were any errors in transcription, ensure it captured what they intended to say; and see if there was anything else they had subsequently thought of, that they wished to alter or add. As the author did the transcription herself, the process of transcribing the recordings deepened understanding of the interview. Starting analysis, immediately after each interview, enabled the author to reflect on the analysis of earlier interviews, and use those reflections, in subsequent interviews, to allow exploration of emerging

themes in more detail. An iterative process of data analysis and data collection was therefore used.

For each interview, the transcript was re-read in full to get an overall sense of the person's journey, and reflect on the meaning of the information given (Creswell, 2009). The transcripts were then systematically analysed. Firstly each transcript was coded manually, by allocating a word, or short phrase, to summarise each short section of text. Sometimes, a phrase from the interview itself was used, an 'in vivo' term (Creswell, 2009; Charmaz, 2006). After several unsuccessful attempts to do this on the computer, using a word document and finding that it tended to constrain the analysis into a limited range of structured models; a process of freely annotating the margins of the printed out transcript was used instead. A process of constant comparison was then used (Charmaz, 2006) i.e. systematically looking through each annotated transcript for similarities and differences, then similar ideas were grouped together to form codes. Codes were then grouped into similar concepts and themes hence categories were formed (Strauss & Corbin, 1998). Different colour pencils were used to circle the codes for each emerging category. As would be anticipated when seeking multiple perspectives, not all data supported the emerging categories, so a note was also made of where there were alternative perspectives in some interviews, so that this could be presented in the findings, to demonstrate the credibility of the data (Creswell, 2009).

The author then reviewed and refined the developing categories, which enabled further comparison of the groups, and the development of more abstract categories. The author did this by writing down all the individual categories on sticky labels, and then spread these all out on a large surface so that they could all be seen, then identifying the linkages with arrows, or by overlapping the labels hence gradually pulling together and linking the abstract categories, to draw out the core themes (Neal, 2009). Those key themes were divided into sub-themes related to outcomes, and sub-themes related to the processes that enabled those outcomes. The findings, from these phase 1 interviews with stroke survivors and caregivers, will be presented in chapter 4.

3.12 Interviews with staff - employees and volunteers

After completion of the interviews, with stroke survivors and caregivers, the second stage of phase one, was to interview those involved in the delivery of the ASPIRE programme, including the stroke specialist nurse, rehabilitation assistant, volunteers and those regularly involved in the information sessions. Ethical approval was gained from the local NHS Research and Ethics committee, as part of the original research ethics application, to interview those involved in the delivery of the ASPIRE programme.

All nine of those regularly involved in the delivery of ASPIRE, were sent an information sheet and invited to participate by letter. The key risks and benefits of participating in the research study were clearly identified in the participant information sheet (see appendix 2). Informed written consent was sought, and gained, before any participation in this study (see appendix 3). For those agreeing to participate in an interview, a mutually convenient time and place (either the hospital or the individual's home) was agreed. Staff interviewed included volunteers, in addition to paid health and social care staff.

There were two parts to the staff interviews; firstly to understand more about the staff's role, their reflections on how the group was run, and the context and process of the ASPIRE programme, in order to contribute to the development of the ASPIRE programme, and to understand more about how ASPIRE could be replicated elsewhere. The second aspect to the staff interviews was to seek the staff views of the experiences, and impact of, the ASPIRE programme on participants. The questions relevant to this aspect are in **bold** in table 12. Other than the volunteers, the staff had not been through the ASPIRE programme themselves, so their data did not form part of the analysis of the outcomes from the ASPIRE programme. Instead, their perspectives enabled the author to reflect on her assumptions and interpretations of the participant data. In order to maintain clarity, and focus, on the data from participants and understand the impact of the ASPIRE programme on participants, without contamination by staff perceptions; all staff interviews took place after the gathering and analysis of participant data (stroke survivors and caregivers).

A semi-structured interview process was used, with the initial plan of questions to ask detailed in table 12. Additional questions were added, to seek clarification of points raised by the interviewee. All interviews took place, in a place of the interviewees choosing, usually a quiet room in the hospital or the interviewees own home. A digital voice recorder was used to record the interviews, which were transcribed as soon as possible afterwards. Interviews took between 30 and 90 minutes, depending on how much the interviewee had to say.

Table 12: Interview schedule for staff and volunteers

| |
|--|
| So you've been working with the ASPIRE group for some time. How long has that been now? |
| In your experience are you able to say what impact you think the ASPIRE programme has on stroke survivors and their caregivers? |
| And how do you think it impacts on their ability to look after their own condition and stop themselves having another stroke – so the secondary prevention? |
| And what about in terms of the recovery and rehabilitation from the stroke side of things – what do you think the ASPIRE group does in terms of that? |
| If someone were trying to set up another ASPIRE group somewhere else is there something about the way the programme is run (something about the way the staff are) that gets the outcomes it gets? |
| And what skills do you think you bring to the group and what skills have you learned or developed as a result of being involved in the group? |
| (How is this different from the cardiac rehab group?) |
| Is there anything you think should be changed about the way the ASPIRE group runs? |
| If you were to leave tomorrow and someone else came into your role, what do you think their induction programme should look like to help them support the ASPIRE programme – what should it include? |

A copy of their transcribed interview was sent to each interviewee for them to review, and amend if appropriate, though no amended transcripts were received. The data protection act was taken into account, in relation to the storage of data. To ensure confidentiality, all files and memory sticks were password protected, not stored on a shared computer, and all data was anonymised. Audio-tapes, transcripts and all other data were stored in a locked filing cabinet, within a locked office on NHS property. Pseudonyms are used throughout. The findings from these interviews were not thematically analysed but instead were used to inform the fourth PDSA cycle – see chapter 4. Having discussed phase 1, the author will now move on to phase two, which looks at the potential outcome measures to be used.

3.13 Phase 2 Research method – quantitative outcome measures

The objective of phase two of the study *was to evaluate; whether identified, validated tools were able to demonstrate a change, over the 12 week ASPIRE programme*. In part, this was assessing the ‘fit’ of the tool, to the outcomes identified during phase 1 in terms of; how closely matched the tool was to the outcomes; and also in terms of ability to assess outcomes for a wide range of participants. In addition, this was an attempt to quantify any change, assessed by the outcome tools, over the 12 weeks of attending.

3.14 Ethics

Ethical approval, for phase 2 of the study, was granted at the same time as for phase 1, in 2008, by the local NHS Research and Ethics committee (reference 08/H0205/14; see Appendix 1). As it was not known what outcomes would be assessed for, the ethics application referred only, to the likelihood of phase 2 being either questionnaire based and / or physical based outcome assessments. One of the consequences of conducting this research project, in the place in which the author, as chief investigator worked (Butler, 2003), was whether or not it was ethical, to ask those attending the 'ASPIRE' programme, to consent to being part of a research project, when they may also feel dependent on the chief investigator for their continued healthcare, and under pressure to participate. Although it was planned to use a third party, (i.e. members of the inpatient stroke team), to approach potential research participants, this proved impractical due to the increasing number of referrals, from a wide variety of sources including; stroke coordinators, TIA clinic, consultant stroke physicians from other local hospitals and general practitioners. Instead, the letters inviting participation were sent out by the author as the chief investigator from her university address. At the time, the author very rarely saw inpatients on the acute stroke unit, so was likely to be viewed as an outsider, when potential participants decided to participate. As a key member of the team running the ASPIRE programme, the author could not be blinded from the knowledge of their participation status; however, there was a risk that this knowledge might influence the author’s behaviour, toward those participating in the research.

The key risks, and benefits, of participating in the research study, were clearly identified in the participant information sheet (see appendix 9); and informed written consent was sought, and gained, before any participation in this study (see appendix 10). If the author had had any doubt, about a potential participant's ability, to give informed consent, due to communication difficulties, then the opinion of the participant's speech and language therapist would have been sought. This was not needed for any of the participants in the study, possibly as those with more severe communication difficulties did not respond to the invitation to participate in the study. If the author had had any doubt about a potential participant's ability to give informed consent, due to cognitive difficulties, then a Mini Mental State Examination score of >24/30 would have been used for inclusion. Again, this was not needed, as those with cognitive difficulties, tended not to respond to the invitation to participate in the study.

The Data Protection Act (Office of Public Sector Information, 1998) was taken into account, in relation to the storage of data for the research project. To ensure confidentiality, all files and memory sticks were password protected, not stored on a shared computer and all data were anonymised. Consent forms, completed questionnaires, and all other data were stored in a locked filing cabinet, within a locked office on NHS property. The inclusion and exclusion criteria, for participation in this phase of the study, are identified in table 13.

Table 13: Inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|--|---|
| Adults following stroke (diagnosed either clinically or medically and documented in their medical notes or referral letter) who were referred to the 'ASPIRE' programme from the start of phase 2. | Those people with stroke for whom there was insufficient time from referral to ASPIRE start date for informed consent to be obtained. |
| Informal carers (as defined by the person who had had a stroke) who attended the 'ASPIRE' programme with a stroke survivor who was participating in the study. | Those stroke survivors with insufficient cognitive or language skills to complete the questionnaires. |
| Those able to give informed consent to participate in the study. | |

3.15 Overview - recruitment to study and data collection

Referral to 'ASPIRE' is offered to; all those who have had an acute stroke confirmed by clinical examination +/- CT scan, or those who have had a TIA and, in the opinion of the referrer, would benefit from the support ASPIRE offers in addressing lifestyle risk factors. The majority of referrals, come from the inpatient stroke team, who offer patients a referral to the ASPIRE programme, just prior to discharge. A number of stroke and TIA referrals are also received from; the TIA clinic physician, the stroke coordinator, community stroke team and general practitioners. Those referred should be able to attend, for 12, once weekly sessions and live in the catchment area for the NHS foundation Trust. On receipt of a referral to the ASPIRE programme, patients were contacted by telephone by the stroke team administrator, to check they still wished to attend, and to arrange their first appointment, at a time convenient to them, and the appointment confirmed in writing.

A letter, plus the participant information sheet (see appendix 9), was sent out from the chief investigator's university address, a day or two after the ASPIRE appointment letter (see appendix 7), inviting them to participate in the phase 2 research. Those responding positively, by reply slip, to participate in the research study, were telephoned in order to answer any questions, then sent the research questionnaires (see appendix 8) by post, along with a consent form (see appendix 10), prior to the participant's first attendance at ASPIRE. Consent forms were signed, and research questionnaires checked and / or completed, at participants' first ASPIRE attendance.

On participants' last attendance at ASPIRE, a repeat set of questionnaires were given, plus postage paid envelopes provided, for return of the questionnaires, to allow participants to have sufficient time, to complete the questionnaires undisturbed. Thus, participants were blinded to their pre-ASPIRE answers. A reminder letter, with a stamped addressed envelope, was sent a month or so later, to those participants who had not yet returned their questionnaires. A further reminder letter was sent to any remaining non-responders.

3.16 Phase 2 - Outcome tools

The process of identifying these tools, and the plans for prospectively testing out these tools, with participants in the ASPIRE programme, (i.e. phase 2 of the sequential mixed methods study) are described below. In phase 2, the sub-themes linked to the key themes identified in phase 1, were used to search for standardised validated tools (see Table 14). These tools were then used to evaluate the ability, of those validated tools, to capture the impact of the ASPIRE programme, on a further cohort of participants. The detail behind the key themes identified in phase 1, are discussed in chapter 4, but summarised here in order to explain the methods used in phase 2.

Table 14: Phase 2 search terms linked to phase 1

| Themes | Sub-themes - outcomes |
|---|---|
| A life I like: the confidence to do the everyday activities important to a person after a stroke | <ul style="list-style-type: none">● Increased confidence |
| Changing hearts and minds: the confidence, knowledge and health behaviour change to reduce vascular risk after stroke | <ul style="list-style-type: none">● Increased self-efficacy (knowledge, skills & confidence) – stroke survivors & caregivers● Behaviour change |
| In the same boat: the benefits of peer support for stroke survivors and caregivers | <ul style="list-style-type: none">● Improved mood● Relief from caregiving● Peer support |

A comprehensive literature search was conducted using the following electronic databases; Allied and Complementary Medicine (1985 to December 2010), British Nursing Index (1994 to December 2010), Citation Index for Nursing and Allied Health (CINAHL) (1982 to December 2010), EMBASE (1974 to December 2010) and MEDLINE (1951 to December 2010). The search was limited to peer-reviewed publications in English with human adult participants. Studies of all designs were included from meta-analyses and systematic reviews to randomised controlled trials, case controlled trials and non-randomised studies.

The Boolean search terms, used to identify appropriate outcome tools, to use to evaluate the ASPIRE programme (with truncations denoted by*) were:

(Stroke* or Cerebrovascular* Or Cerebral vascular* or Ischemic stroke* or TIA or vascular) in Title

AND (Scal* or Rat* or Tool* or Assess* or Measur* or Outcome* or Test or Eval*) in Title

AND (Confidence or Self-efficacy or Behavio* or Mood* or Knowledge or Care* or Peer* or Support*) in Title

Of the 956 hits, 840 studies were excluded by title, as irrelevant to the review question; i.e. what outcome tools can be used to evaluate the ASPIRE programme? The abstracts of the remaining articles identified, were then reviewed, to identify papers which referred to outcome tools, either in terms of their development; their use in previous research or in terms of analysis of their psychometric properties. Manual searches, of the reference lists of the articles retrieved, were searched to identify additional relevant articles. In addition, SCOPUS was used to identify other relevant literature. A total of 44 relevant studies were identified, which between them, considered a total of 23 different outcome tools. This included multiple tools, to choose between, for assessing some factors such as mood; whereas, only one tool was found to assess stroke knowledge.

Consideration of the need to use the tools chosen, for both the research study and for on-going routine clinical practice, influenced the final choice. Greenhalgh et al (1998) suggest consideration of feasibility, psychometrics, utility and user-centredness, to evaluate an outcome measure for use in routine practice. Fitzpatrick et al (1998) use slightly different terminology, and go into more detail; however, many of the key concepts identified, are very similar. Fitzpatrick et al (1998) suggest that, in choosing a measure for a clinical trial, consideration should be given to feasibility, reliability, validity, responsiveness, precision, interpretability, appropriateness and acceptability.

Feasibility, which refers to whether an outcome measure can actually be practically used in a particular context, is an important consideration, as it includes factors such as cost, and the need for training in the use of the outcome measure. Utility and appropriateness are related concepts, and include the time

needed to use the measure, the method for measuring outcome such as; observation or self-completion questionnaire; whether that method is likely to capture the required data; and whether the measure was developed for the type of situation, and client group, being measured. Feasibility, utility and appropriateness are insufficient to give an outcome tool merit; psychometric properties such as reliability, validity and responsiveness or sensitivity of the measure, also need to have been robustly tested.

Reliability, is the ability of an outcome measure to produce consistent findings when, that which is being measured remains the same, irrespective of who is doing the measuring, and also over time i.e. test-retest reliability (Fitzpatrick et al, 1998). Validity is also required; the outcome measure should measure what it is intended to measure, so for instance, a measure of gait speed, will not measure balance. Finally the measure must be responsive and sensitive; able to detect change accurately and with precision. The measure should also cover the range of values expected, and not either measure values that are too low or high, for those under evaluation i.e. a floor or ceiling effect. The most important attributes for this study used to screen the outcome tools identified; were considered to be feasibility, and appropriateness, particularly being validated for use in stroke, and considering language or cognitive impairments. The final tools chosen, all self-completion questionnaires, are summarised in table 15 and can be found in full in appendix 8.

Table 15: Standardised tools used in phase 2

| <u>Standardised tool</u> | <u>Used to identify</u> | <u>Used with</u> |
|--|--|---------------------|
| Stroke Self-Efficacy Questionnaire (Jones et al, 2008) | Self-efficacy | Person after stroke |
| Cerebrovascular Attitudes and Beliefs Scale (CABS-R) (exercise subscale) (Sullivan & Waugh, 2007). | Health behaviour change in relation to attitudes to exercise | Person after stroke |
| Stroke Knowledge Test (Sullivan & Dunton , 2004) | Knowledge of stroke and factors related to secondary prevention. | Person after stroke |
| Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). | Mood | Person after stroke |
| Caregiver Strain Index (Robinson, 1983) | Caregiver Burden | Carer |

The outcome tools considered are listed, with the main findings from the screening process summarised, in tables 16- 20; with the main reason for choosing or rejecting each tool, highlighted in bold. The tools are then described, and critically evaluated, in light of published evidence; including the purpose, background, psychometric properties and method of scoring.

Self-efficacy

Three possible tools, to assess self-efficacy were identified, as shown in table 16. The Stroke self-efficacy questionnaire was chosen due to being the only stroke specific tool.

Table 16: Outcome tools identified – self efficacy

| Self-efficacy | | | |
|---|----------------------------|---|-----------------|
| Measure | Appropriateness | Feasibility / Notes | Decision |
| Stroke self-efficacy questionnaire (Jones et al, 2008) | Stroke specific. | Freely available. Good face validity and feasibility in the recovery period after stroke. Permission given by author for its use. | Yes |
| Falls Efficacy scale (Tinetti et al, 1990) | Not stroke specific | Developed for use with people after a fall rather than stroke. | No |
| Activities-specific Balance Confidence Scale (Powell & Myers, 1995) | Not stroke specific | | No |

Stroke Self-Efficacy Questionnaire (SSEQ) (Jones et al, 2008)

The SSEQ is a questionnaire, designed to measure individual confidence, in functional performance after stroke. The measure consists of 13 items, which the respondent is asked to rate their confidence in performing, on a 10 point visual analogue scale, giving a minimum score of 0 (least confident), and a maximum score of 130 (most confident). Items include those related to transfers, mobility, upper limb function, exercise and participation (see appendix 8a). As the data generated from the SSEQ are based on a visual analogue scale, they can be treated as interval / ratio data for statistical analysis purposes as long as they are normally distributed (Hicks, 2009).

The Stroke Self-Efficacy Questionnaire was developed between 2004 and 2006, in 3 separate studies (Item Generation, Instrument Development & Validity Study) (Jones et al, 2008). The SSEQ was designed specifically, for use with people after stroke, to measure an individual's confidence, to achieve specific tasks after stroke, and their confidence to continue their progress, after discharge from rehabilitation services. The SSEQ was developed with stroke survivors, between 2 and 24 weeks post-stroke; a similar time after stroke to the majority of ASPIRE participants, though with a focus on the rehabilitative aspects of stroke, as opposed to secondary prevention. The SSEQ has been shown by its developers to have good face validity and feasibility, in the recovery period after stroke, and good internal consistency; however, a ceiling effect has been identified in those with high levels of mobility and independence, in activities of daily living (Jones et al, 2008). In addition, those with difficulty reading or following a 2-step instruction were excluded from the development of the SSEQ, so it is unclear whether it can be used with those with communication or cognitive impairment (Jones et al, 2008).

The Falls Efficacy scale and Activities-specific Balance Confidence Scale were also considered but discarded, as they are not relevant for the significant proportion of participants without balance difficulties; whereas, the Stroke Self-efficacy questionnaire encompasses many issues, relevant to the majority of those who have had stroke.

Health behaviour change

Three possible outcome tools were identified (see table 17) to assess health behaviour change, with the cerebrovascular attitudes and beliefs scale being chosen, as the only stroke specific tool.

Cerebrovascular Attitudes and Beliefs scale (Sullivan & Waugh, 2007).

The CABS-R (see appendix 8b), is a stroke specific tool to assess attitudes and beliefs, towards a number of key lifestyle factors, relevant to reduction of risk of further stroke. The CABS-R was developed, in line with the Health Behaviour Model, and assesses; beliefs about the benefits and barriers to undertaking preventative behaviours, plus beliefs about the susceptibility and severity of stroke. Subscales exist for exercise, cholesterol, weight and alcohol (Sullivan et al, 2010).

All beliefs are rated on a 5 point Likert Scale; Strongly Disagree, Disagree, Neutral, Agree and Strongly Agree; being scored from 1 (minimum) to 5 (maximum). Higher scores represent; greater exercise self-efficacy i.e. that exercise would be easy and not associated with significant barriers; acknowledgement that exercise is consistent with the subjective norm and has benefits in terms of reducing stroke risk; and also indicate greater perception of susceptibility to stroke and the seriousness of stroke.

Table 17: Outcome tools identified – health behaviour change

| Health behaviour change & attitudes to exercise | | | |
|--|----------------------------|--|-----------------|
| Measure | Appropriateness | Feasibility / Notes | Decision |
| Cerebrovascular Attitudes and beliefs scale (CABS-R) (Sullivan & Waugh, 2007). | Stroke specific | Has several subscales including one for exercise | Yes |
| Short outcome expectations for exercise (SOEE) (Resnick et al, 2000) | Not stroke specific | | No |
| Short self-efficacy expectations for exercise (SSEE) (Resnick & Jenkins, 2000) | Not stroke specific | | No |

Scores are totalled, to give an overall score on the CABS-R exercise subscale. As ordinal data; however, relative but not absolute meaning, can be ascribed to the scores. As the data generated from the CABS-R are based on a Likert scale, statistical analysis requires a non-parametric test (Hicks, 2009). In terms of psychometric properties, the CABS-R has been shown to have moderate to good internal consistency (Sullivan et al, 2009) with scores that are relatively stable over time i.e. good test-retest reliability (Sullivan et al, 2009). However, there is limited data about the user’s perspective, plus a lot of repetition between the different subscales within the CABS-R.

It has been shown that beliefs about the benefits, susceptibility and self-efficacy in relation to exercise, predict behaviour to reduce stroke risk (Sullivan et al, 2009). In contrast, in relation to weight loss, beliefs about barriers, susceptibility and

subjective norms also play a part (Sullivan et al, 2009). Therefore, in order to gain a fuller picture of an individual’s health beliefs in relation to risk factors, all of the subscales would have to be used. This approach assumes, that an individual’s beliefs about his/her risk of stroke, are restricted to one of the existing subscales; whereas, in the author’s experience, many stroke survivors have a much wider range of beliefs, about how lifestyle factors affect stroke risk, including; the impact of stressful life events, other illnesses and medications, diet and smoking. Only the exercise subscale was used for this study, as every ASPIRE participant is supported to have health beliefs and behaviours, in relation to exercise. Although ASPIRE participants are also supported to change other health beliefs and behaviours where relevant e.g. weight loss, reduction in alcohol intake, smoking cessation, these are not applicable to all participants.

Due to the focus on exercise in terms of health behaviours, the SOEE and SSEE were also considered. These, like the CABS-R, are also fairly newly developed scales, based on self-efficacy theory, with similar levels of data about psychometric properties, such as reliability and internal consistency (Resnick & Jenkins, 2000). There is limited data about their use, with those later after stroke; at least 6 months (Resnick et al, 2007) or approximately 5 years (Shaughnessy et al, 2006); but not in the first three months after stroke. No studies have compared the CABS-R exercise subscale with the SOEE or SSEE scales; however, since self-efficacy expectations, are specific to the situation and context, the CABS-R exercise subscale was used, as it was developed specifically for use with stroke.

Knowledge of stroke and risk factors

Only one validated outcome tool to assess knowledge of stroke and risk factors was identified (see table 18).

Table 18: Outcome tools identified – Knowledge of stroke & risk factors

| Knowledge of stroke & risk factors | | | |
|--|------------------------|--|-----------------|
| Measure | Appropriateness | Feasibility / Notes | Decision |
| Stroke knowledge test (Sullivan & Dunton , 2004) | Stroke specific | Permission given by author to modify to make it UK rather than Australia specific. No other tool found to assess stroke knowledge in stroke survivors. | Yes |

Stroke Knowledge Test (SKT) (Sullivan & Dunton, 2004)

The SKT was developed to directly measure, change in knowledge about, and understanding of stroke, including factors related to secondary prevention. The SKT consists of 20 questions, each with 5 possible answers, giving a minimum score of 0, and a maximum of 20. (see appendix 8c). The SKT was designed so that questions have only 1 right answer, plus 3 detractor answers and an 'I don't know' option. Although this is true for some questions e.g. Question 4 "Which age group is more at risk of stroke" for which the answer is option d) '61+'; some questions arguably have more than one right answer. Question 16 "Which of the following is an example of a physical disability caused by stroke" has the following options: a) The right arm is paralysed, b) There are problems with memory, c) Unable to speak properly, d) Having trouble doing things in the correct order. Arguably both answers 'a' and 'c' could be correct. Some other questions had 3 correct answers, then an 'All of the above' option. Answers were scored either as 'Incorrect', 'I don't know', 'Correct' or 'Partially Correct' when at least one, but not all of the possible correct answers, were identified (see appendix 8c). As the data generated from the SKT are ordinal, the data has relative but not absolute meaning and statistical analysis requires a non-parametric test (Hicks, 2009).

The SKT was developed, by systematic generation of test items, from a literature review, which were then piloted and reviewed, before final item selection was made (Sullivan & Dunton, 2004). Initially developed with university students and relatives of those with stroke (Sullivan & Dunton, 2004), so not developed for use by those with communication or cognitive difficulties, the SKT has since been used with stroke survivors (Sullivan & Waugh, 2005). The SKT has been tested, for sensitivity to different levels of stroke knowledge and reliability, by stroke survivors and the general public in Australia (Sullivan & Dunton, 2004).

Normative data is available for Australia, which shows that stroke survivors and caregivers (related or not related to a stroke survivor), were able to answer half of questions correctly (Sullivan & Waugh, 2005). As the SKT has not been previously used in the United Kingdom, written permission was given by Karen Sullivan, developer of the Stroke Knowledge Test to modify this scale; hence, question 14 was

reworded to ask “Approximately how many people in the UK are affected by stroke every year?”, rather than “Approximately how many Australians are affected by stroke every year?”

Mood

A large number of outcome tools were identified (see table 19), which had been used for assessing mood in stroke; however, the majority only assess depression and not anxiety. This was considered an important issue, by the author, who had witnessed anxiety in many stroke survivors. The Hospital Anxiety and Depression Scale (HADS), and the General Health Questionnaire – 30 (GHQ-30), have been found equal in their ability to measure both anxiety and depression, in those 6 months after stroke (O’Rourke et al, 1998). The HADS scale has been found to be shorter, simpler to use and more sensitive than the GHQ-30 (O’Rourke et al, 1998).

The HADS was chosen for this study, due to its utility for both the research study and for ongoing clinical practice. The HADS is a self-rating scale, which assesses mood, in terms of the level of both anxiety and depression experienced, and has been in wide use in both clinical practice and research, since its initial publication (Zigmond & Snaith, 1983) (see appendix 8d). It was developed for use with general medical outpatients, whose diagnoses were not specified, so is not stroke specific (Zigmond & Snaith, 1983).

Table 19: Outcome tools identified – Mood

| Mood | | | |
|--|------------------------|---|-----------------|
| Measure | Appropriateness | Feasibility / Notes | Decision |
| Hospital anxiety & depression scale (Zigmond & Snaith, 1983) | Not stroke specific. | Has been used for assessing anxiety and depression in stroke over a similar timescale to this study (De Wit et al, 2008). | Yes |
| General Health Questionnaire – 30 (GHQ-30) | Not stroke specific | Can assess anxiety and depression however less sensitive and not as short and simple to use as HADS (O’Rourke et al, 1998). | No |
| Signs of Depression scale (Hammond et al, 2000) | Not stroke specific. | An observational scale more appropriate for an inpatient rather than an outpatient setting. Assesses low mood but | No |

| | | | |
|--|--|--|-----------|
| | | not anxiety (Bennett et al, 2006). | |
| Beck Depression Inventory (Beck et al, 1961). | | Measurement of depression but not anxiety. | No |
| Hamilton Depression rating scale (Hamilton, 1967). | | Measurement of depression but not anxiety. | No |
| Geriatric depression scale (Yesavage et al, 1983). | | Measurement of depression but not anxiety. | No |
| Self-rating depression scale (Zung et al, 1965). | | Measurement of depression but not anxiety. | No |
| Centre for Epidemiologic Studies – Depression scale (Radloff, 1977). | | Measurement of depression but not anxiety. | No |
| Depression Intensity Scale Circles (Turner-Stokes, 2005) | Stroke specific. Designed for use in aphasia. | Measurement of depression but not anxiety. | No |
| Visual Analogue Mood Scale (Stern, 1997) | Stroke specific however appropriate for assessing low mood but not anxiety (Bennett et al, 2006). | May not be completed accurately by those with cognitive or visuospatial impairments (Price et al, 1999). | No |
| Visual Analogue Self-esteem Scale (Brumfitt & Sheeren, 1999) | | May not be completed accurately by those with cognitive or visuospatial impairments (Price et al, 1999). | No |
| Stroke Aphasic Depression Questionnaire (Sutcliffe & Lincoln, 1998) | | | No |

Hospital Anxiety & Depression Scale (HADS) (Zigmond & Snaith, 1983).

The HADS consists of 14 questions; 7 of which assess symptoms of anxiety, and 7 of which assesses symptoms of depression. Each question is self-rated from 0 points; no symptoms, to 3 points; maximum, giving an overall maximum total of 21 points for each of the anxiety and depression subscales. It is thought that a total score of 11 or higher for a subscale indicates a probable mood disorder, with scores of between 8 and 10 for a subscale, indicating a possible mood disorder (Bjelland et al, 2002). As the data generated from the HADS are ordinal, the data has relative but not absolute meaning and statistical analysis requires a non-parametric test (Hicks, 2009).

Although originally designed for use in the inpatient phase, the HADS has been tested in other settings, can be used face-to-face or over the telephone (Hoffmann et al, 2010), making it particularly useful for a research setting, where gathering complete follow up data is important. Although not designed for use with those with marked communication problems, this group of patients would not meet the inclusion criteria for this study, so this was not an issue. The HADS has been used for assessing mood longitudinally over a similar timescale to this study i.e. at 2, 4 and 6 months after a stroke (De Wit et al, 2008).

Caregiver burden

Several tools were identified to measure caregiver burden, as shown in table 20 with the Caregiver Strain Index being chosen, as the simplest and most concise tool; to avoid adding additional burden to the caregivers in completing the tool.

Caregiver Strain Index (Robinson, 1983)

The Caregiver Strain Index (CSI) (see appendix 8 e) was developed, for use with those caring for patients with heart disease and people after hip surgery; rather than for stroke (Visser-Meily et al, 2004). However, it is the most commonly used scale in stroke to measure the burden of informal care giving (Visser-Meily et al, 2004); as it is simple, concise and recommended for use in both clinical practice and research (Job et al, 2004). The CSI can also be used face-to-face or over the telephone (Hoffmann et al, 2010), making it particularly useful for a research setting, where gathering complete follow up data is important. Although a somewhat nebulous concept, caregiver burden can include emotional, physical, psychological, social and financial elements (Visser-Meily et al, 2004).

The Caregiver Strain Index consists of 13 questions, requiring a 'Yes' or 'No' response; e.g. 'It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required).' Each 'Yes' response scores 1 point, giving a maximum possible score of 13. The higher the total score, the higher the burden of care experienced. As the data generated from the CSI are ordinal, the data has relative but not absolute meaning and statistical analysis requires a non-parametric test (Hicks, 2009).

Table 20: Outcome tools identified – Caregiver burden

| Caregiver burden | | | |
|---|------------------------|--|-----------------|
| Measure | Appropriateness | Feasibility / Notes | Decision |
| Caregiver Strain Index (Robinson, 1983) | Not stroke specific. | Simple & concise. Most commonly used scale for caregiver burden in stroke though not developed for use in stroke. | Yes |
| Caregiver Reaction Assessment (Given et al, 1992) | Lengthy & complex | In a comparison with Caregiver Reaction Assessment, Self-rated Burden and Sense of Competence Questionnaire the Caregiver Strain Index was found to be one of the best in terms of feasibility and validity (Job et al, 2004). | No |
| Self-rated Burden (Job et al, 2004) | Single item | | No |
| Sense of Competence Questionnaire (Vernooij-Dassen et al, 1996) | Lengthy & complex | | No |

The CSI is one of a large number of tools, designed to assess caregiver burden to enable evaluation of the impact of rehabilitation interventions, and of supportive strategies for caregivers (Visser-Meily et al, 2004; Job et al, 2004). The Caregiver Reaction Assessment, Self-rated Burden and Sense of Competence Questionnaire were also considered; however, the Caregiver Strain Index evaluated best in terms of feasibility, utility and validity (Job et al, 2004). The CSI has been shown to have convergent validity with Caregiver Reaction Assessment, Self-rated Burden and Sense of Competence Questionnaire (Job et al, 2004). Although the CSI is less likely to be totally completed, it gives more detailed information than the Self-rated Burden scale (Job et al, 2004). However limited data exists on the reliability or responsiveness of these caregiver burden tools (Visser-Meily et al, 2004).

3.17 Data analysis

Given the exploratory nature of this phase of research, both in terms of the outcome tools used, and the effectiveness of the intervention, the focus of data analysis was descriptive. Demographics, and other participant characteristics, were collated and presented including; civil and employment status at date of stroke; risk factors and relevant past medical history; type of stroke; residual effects of stroke at time of attendance at ASPIRE including physical abilities, cognition, communication and mood; plus attendance at ASPIRE. Participant flow

was summarised using a flow diagram; reporting referrals to the intervention; numbers approached to participate in the study; numbers recruited; and completion and attrition rates.

Analysis of the results from the five outcome tools included median scores, lower and upper quartiles and inter-quartile ranges. A one-tailed hypothesis was used, as qualitative data from phase one, indicated that the predicted results, were hypothesised, to go in one direction for each outcome tool used (Hicks, 2009). It was anticipated that Self-efficacy scores, CABS-R scores and Stroke Knowledge Test scores would all increase, whereas HADS scores and Caregiver Strain Index scores would be lower, also indicating an improvement. Routinely collected data of blood pressure, weight and girth were analysed using appropriate statistical tests for an experimental, same-subject, design and parametric data (Hicks, 2009).

3.18 Findings and discussion

The finding from the practice development project, and both phases of this mixed methods study, are presented, and the findings and limitations critically discussed in chapter 4. The baseline (pre-ASPIRE) and post-intervention (post-ASPIRE) results, for each of the five outcome tools, are presented along with graphs illustrating individual changes, as it was not known, within such a heterogeneous group of participants, what factors would influence the effectiveness of the intervention.

Chapter 4: Findings & discussion

4.1 Introduction

This chapter presents a critical analysis and discussion, of the development and evaluation of the practice development project 'ASPIRE' ; a multi-factorial, self-management and peer support programme, for stroke survivors and caregivers. As outlined in table 21, a series of five PDSA cycles were used, in the development of this programme.

Table 21: PDSA cycles used in the development of the ASPIRE programme

| PDSA cycle | Timescale | Study component of cycle | Comments |
|------------|--------------------------|---|----------------------------|
| First | Autumn 2006 – April 2007 | Initial informal evaluation, focus group with participants. | 'Life after stroke group' |
| Second | April to December 2007 | Formal audit evaluation in October 2007 | Programme now named ASPIRE |
| Third | 2008-2009 | Phase 1 research data collection (patients & caregivers), transcription & analysis | |
| Fourth | 2009-2010 | Phase 1 research data collection (staff and volunteers), transcription & analysis. | |
| Fifth | 2010 – 2012 | Phase 2 research data collection & analysis | |

In the first part of this chapter, the findings from the first two PDSA cycles are presented, and critically analysed. Data for the final 3 PDSA cycles was provided, through a formal, ethically approved, two phase, and mixed methods research study. Phase 1 of this study involved interviews, to identify the impact of participating in ASPIRE, from the perspectives of a cohort of stroke survivors, their caregivers and the professional staff and volunteers, involved in running the ASPIRE programme. The participant interviews were analysed, using a grounded theory approach, to identify key themes to capture that impact. Once the key areas of impact, of attending the 'ASPIRE' programme, had been identified in phase 1 of the study; phase 2 sought to evaluate; a) Whether those key areas of impact lead

to outcomes; and b) Whether currently existing standardised validated tools were able to assess those outcomes. Due to the heterogeneity of participants in the ASPIRE programme, finding a single standardised tool, that captured all of the elements identified in the interviews, proved impossible. It was decided to identify a selection of outcome tools, from the literature, aligned to the main areas of impact identified in phase one; and prospectively test out these tools, with a further cohort of participants in the ASPIRE programme. The results for each of the outcomes tools used are presented; the findings and limitations plus other routinely used measures, such as weight, girth and blood pressure are also discussed. The remainder of this chapter will be structured under the heading of Plan-Do-Study-Act for each PDSA cycle.

4.2 PDSA cycle 1 - January – April 2007

PDSA 1: Plan

As discussed in chapter 3 section 3.4, the initial intervention was planned to be a rolling recruitment, group based, face to face, self-management programme, supported by an individual, in-depth interview and which included both stroke survivors and caregivers and also included an exercise component.

Exercise

It is known that a successful group exercise programme requires sufficient space, changing areas, drinking water and an appropriate environment, in terms of temperature, floor surface and ventilation (Glynn & Fiddler, 2009), so the programme was held between 4 and 5pm, once a week, as the only time when staff were available and a rehabilitation area was free in the hospital.

At their first attendance, each participant was assessed by the author, to identify their current fitness levels, physical and functional abilities and the level of supervision required, plus safety issues, including the individual's balance and ability to follow instructions (Glynn & Fiddler, 2009). No formal graded, pre-exercise testing was undertaken, as with such an inclusive cohort, many individuals would be incapable of performing at the levels suggested (Gordon et

al, 2004; Ivey et al, 2005). Instead, a physical assessment was carried out including; blood pressure measured using a manual or automatic sphygmometer; weight measured using portable scales; strength assessed manually using the Oxford scale; balance assessed using the standing elements of the Berg Balance Scale (Berg et al, 1992); plus coordination, dexterity and mobility, assessed in functional activities such as; walking into the department, removing and hanging up a coat and using a pen. An exercise circuit, aimed at improving cardiovascular and general fitness plus strength, was set up, though constrained by the equipment and space available. The circuit included; sit-to stand; step-ups; balance board; push the gym ball up the wall; bed exercises such as bridging; upper limb free weights; shuttle walk and exercise bike. All stroke participants followed the same basic circuit of exercises, moving round every 3 minutes and modified to allow for differences in impairment. For instance, at the sit-to-stand station, the height of the seat, the number of repetitions and the length of rest between each repetition / set, were all individually prescribed.

The author's clinical judgement and experience, plus the Borg rating of perceived exertion scale (Borg, 1970), were used to monitor the intensity. A systematic review by Pang et al (2013) identified strong evidence of benefits, such as enhanced aerobic fitness, walk speed and endurance, from 20-40 minutes of aerobic exercise, 3-5 days a week, in those with mild to moderate stroke. Aerobic exercise was defined as 40-50%, building to 60-80% of heart rate reserve (HRR). Heart rate reserve was calculated using the formula; $HRR = \text{Maximum heart rate} - \text{resting heart rate}$. Maximum heart rate was estimated, using $208 - 0.7 \times \text{age}$ (Tanaka et al, 2001), as this equation was derived in a study that included older adults. The Karvonen formula was then used to calculate target exercise heart rate i.e. $\text{Exercise heart rate} = \% \text{ target intensity} (\text{HR max} - \text{HR rest}) + \text{HR rest}$.

In most cases, this meant aiming for moderate levels of intensity (12-14), which equates to heart rates of 120 – 140 beats per minute (bpm), and is described as 'somewhat hard' to 'hard' (Borg, 1970). For an overweight 50 year old, with a resting heart rate of 90, a theoretical maximum heart rate of 173 ($208 - 0.7 \times 50$), and low pre-stroke levels of fitness, the target exercise intensity might be 40%;

thus an exercise heart rate of $40\% (173 - 90) + 90 = 122$ pm. For a previously fit 90 year old farmer, with a resting heart rate of 78, and a target intensity of 75%, the exercise heart rate would be $75\% (145 - 78) + 78 = 128$ bpm. As the programme only ran once a week, the key to realising the benefits of aerobic exercise was to work with participants, to help them identify ways of exercising during the rest of the week, plus helping each individual to recognise when they were working at the right intensity for them, at that stage of their progress.

Each stroke participant had a record sheet, on which they recorded information about their exercise such as; how many repetitions and sets of each exercise they completed within the 3 minutes; or how heavy a weight they were using, which enabled participants to record their own progress. A circuit based, lower limb focused programme was used, as it is recognised as an effective intervention in stroke. It also allows; exercises to be individually tailored in terms of type, intensity and number of repetitions; a larger group to attend despite limited numbers of individual pieces of equipment and therapist time; plus encourages peer support and social interaction (Wevers et al, 2009; Kim et al, 2016)

Self-management and information provision

At their first attendance, each participant had a discussion with the author, in which they identified their goals, and any concerns about their secondary prevention. To encourage task mastery, a key component of self-efficacy, the author supported participants to identify small, achievable, short term goals as well as longer term ambitions. Each week, a half hour group information session was held, to encourage participants to self-manage. These sessions were in the form of interactive discussions, led by members of the stroke multi-disciplinary team, including physiotherapist, nurse, occupational therapist, stroke coordinator and social worker. Rather than just provide information content, the discussions checked and added to participants understanding, and sought and challenged participants' beliefs, in relation to stroke and risk factor management. In order to increase self-efficacy through vicarious experience, the facilitators encouraged sharing of ideas, and brought in examples of what others had done from their own past experience. The discussions were focused on the topics identified by Young

& Forster (2007); i.e. risk factors (smoking cessation, eating a healthy diet, stress management and medicine management); and life after stroke (getting around - mobility and driving, local services and support groups, mood, cognition and memory, managing relationships and sexual issues, travel and holidays, financial advice, return to work, leisure and new roles). Discussions often went off-topic, as facilitators responded to issues raised by participants: this ensured a more individually tailored information session, despite the involvement of a group.

The verbal information provided by the discussions was supported by information in a variety of formats, to take account of variable literacy levels (Stonecypher, 2009). These included; various books, cassettes, compact discs, videos and DVDs about stroke; plus leaflets and fact sheets produced by the Stroke Association. There is evidence that, although written information supports knowledge and recall of health information, alternative formats such as audio and video recordings can, in addition, improve health knowledge, health behaviour and self-efficacy (Colledge et al, 2008). As it is known that information needs change in relation to time after stroke (Hanger et al, 1998), it was anticipated that as the programme lasted several weeks, it would give the opportunity to modify the information provided, in relation to time post- stroke, as well as giving the opportunity for repetition and reinforcement, to support knowledge acquisition.

PDSA 1: Do

The 'Life after Stroke' programme was started in January 2007. Four people were identified by the author, and a stroke unit based colleague, early in the New Year and invited to start together on the first week. One new person was invited to join the programme each week thereafter, wherever possible. This allowed sufficient time for them to have their assessment, induction and goal setting prior to the exercise session. One participant even started on the last day of her acute inpatient stay. A summary of this first programme is given in Table 22.

Table 22: Initial life after stroke programme

| | |
|--------------------------|---|
| Name of programme | Life after stroke Yeovil (L.A.S.Y.) |
| Assessment | Brief individual physical assessment of the stroke survivor to identify residual stroke deficits or comorbidities that might limit or impact on participation in exercise plus blood pressure & weight. The assessment and a discussion about the rehabilitation aims of attending the programme took place prior to the rest of the group arriving. |
| Participants | A total of 8 stroke survivors and 5 caregivers. Most stroke survivors aged 80 years or less and with minor residual impairments. Caregivers were a close family member, usually a daughter or a spouse. |
| Exercise session | 30 minutes of predominantly cardiovascular exercise in day hospital rehabilitation room. Each stroke survivor spent 3 minutes at each station on a circuit. Circuit included step ups, sit-to stand, upper limb weights, exercise bike, wobble board, bridging & other bed exercises and marching on the trampette. Encouragement was given to gradually increase the number of repetitions or level of exercise as they felt able to. Some caregivers stayed in the rehabilitation room and chatted to each other, discussed issues with the stroke nurse consultant or accompanied and encouraged the stroke survivor whilst they were exercising, others chose to take a break whilst the stroke survivor was exercising and return in time for the information session. |
| Information session | 30 minutes interactive discussion in day hospital rehabilitation room. Sessions were smoking cessation and other lifestyle factors, eating a healthy diet, stress management, medicine management, exercise, local services and support groups, mood, cognition and memory, managing relationships and sexual issues, travel and holidays, financial advice, return to work, leisure and new roles. |
| Supporting documentation | Individual exercise record sheet kept by staff, handed out each week to participants to complete then filed in their medical records. |
| Staffing | Consultant therapist – rehabilitation plus Consultant nurse – Stroke |
| Timing | 12 week programme held on Thursdays 4- 5pm |

PDSA 1: Study

In this first PDSA study phase, the author and her nurse consultant colleague discussed their views of how the programme was running, supported by information from the author's 'praclog'. Two key issues were identified. Firstly it was apparent that the exercise session needed amendment. The rigid 3 minutes per exercise station, took no account of the wide variation in impairments, fitness levels or age of participants, so some ended up doing a 'double session' at one station, while others had a rest station as needed. In addition, as there was no cardiovascular equipment available, it was mainly a task-based circuit with activities such as step ups, repeated sit to stand and balance board. These activities were too challenging for those with residual physical deficits, and / or low levels of cardiovascular fitness, due to comorbidities.

Secondly, take up to the programme was limited, as all those invited to participate, had just been informed that they were not allowed to drive for a month from the date of their stroke; and also tended to be too mobile to be eligible for hospital transport. This is a significant issue in a dispersed and predominantly rural population. Stroke participants therefore tended to be those with little residual stroke deficit, who were able to catch a bus to the hospital, or who had a family member who could transport them. The challenge of transport, in rehabilitation after stroke, has also been identified as an issue by other authors (e.g. Logan et al, 2004; Kendall et al, 2007).

In line with the practice development ethos of inclusive, participative, collaborative evaluation (McCormack et al, 2013), informal feedback was sought from the first few participants. A focus group was held, instead of the usual information session, and involved all the current stroke and carer participants. These participants were asked to reflect on the programme using three questions; what should be stopped, what should be started and what should be continued. A focus group is recognised as an effective means of data collection about beliefs and attitudes; although, for research purposes, it can present difficulties in ensuring the confidentiality of all group members (Clarke, 1999). As this information was used purely for practice development, ethical approval was not

sought. The focus group discussions were not recorded in any way at the time; however, the author made notes in her 'praclog' afterwards of the key points of discussion.

The key issues that emerged during the discussion were that all the participants felt very positive about the peer support, and that they had gained in confidence, and knowledge on prevention of further stroke. Some had even continued to attend, despite also regularly attending the gym, and/ or returning to work, during the twelve weeks. They felt; however, that they would prefer a) a venue more focussed on wellness rather than illness, b) a longer exercise session and c) a morning rather than afternoon session. In addition, very few were able to recollect their goals and aims of attending; when reminded of them, all agreed that they had achieved their goals but would like the opportunity for a review.

PDSA 1: Act

The overall positive feedback, was presented in a report, to the regular county wide meeting of NHS providers and commissioners for stroke, who agreed that the feedback was sufficiently encouraging, for the pilot to be allowed to continue, albeit with modifications in response to the feedback received. It was also made clear that a more formal evaluation process was needed. How to implement the modifications needed, plus the need for a more formal evaluation, were considered in the planning phase of PDSA cycle 2.

4.3 PDSA cycle 2 April – December 2007

PDSA 2: Plan

The author decided that an audit would quickly provide the more objective formal evaluation required by the county wide stroke group, and also form the study phase of PDSA cycle 2. In response to the focus group feedback, the author investigated whether there was an appropriate non-health based venue in the community; however, the cost of hiring a venue, plus time and costs for staff travel were prohibitive. Instead, a time was identified when the programme could be held as a one hour exercise session, in the larger outpatient rehabilitation gym

in the hospital, followed by half an hour for the interactive self-management session. Moving to the large gym came at a time when, due to an unplanned reduction in the availability of inpatient rehabilitation beds, nearly half of all those with stroke were being discharged directly home from the acute stroke unit, thus increasing the number of potential participants who were invited to attend. As a consequence, the numbers attending the programme increased and help from a rehabilitation assistant was agreed; to ensure the safety of the session; to instruct or remind participants how to use the gym equipment; and also to make the drinks for the information session, so that two staff members remained in the gym at all times.

During a participant's initial session more individual time was allowed; to assess physical abilities; to identify goals; to provide answers to specific individual queries, often about medication or the results of investigations; and to discuss individual risk factors and their management. The interactive information sessions became more responsive to need, so, for instance, a session on managing medical emergencies including basic life support was included, and the content of the session on roles would vary depending on whether the group included those of working age or not. The additional space and equipment, including a treadmill, static bike, recline bike and wheelchair accessible bikes in the gym, allowed individual goal-oriented exercise circuits, which promoted cardiovascular fitness and actively supported an individual's rehabilitation, rather than a uniform circuit with everyone moving round every 3 minutes. Participant's goals, and planned exercise programme, were recorded on self-held record cards. Participants were advised to start and finish with something they found relatively easy on a low setting as a warm up and cool down; mostly an exercise bike or treadmill; and then to choose their own order for their other exercises. The participants made note of the amount of exercise completed at each station; for instance the level, weight, time or number of repetitions.

After hearing the departmental general manager, referring to the abbreviations L.A.S.Y. as the 'lazy' clinic, it was obvious a new name was urgently required. After lengthy consideration the programme was renamed the '**ASPIRE**'

programme; an acronym for ‘Acute stroke, Self-management support for secondary **P**revention, **I**nformation, **R**ehabilitation & **E**xercise’.

PDSA 2: Do

A summary of the revised intervention, the ASPIRE programme is in table 23.

Table 23: ASPIRE programme April – December 2007

| | |
|--------------------------|--|
| Name of programme | ‘ASPIRE’ ‘Acute stroke, Self-management support for secondary P revention, I nformation, R ehabilitation & E xercise’ |
| Assessment | Individual physical assessment of the stroke survivor to identify residual stroke deficits and comorbidities and determine the most appropriate exercises in line with their goals and abilities plus discussion about their aims of attending the programme Blood pressure & weight recorded. |
| Participants | Up to 12 stroke survivors and their caregivers. Most stroke survivors aged under 80 and with minor to moderate physical, cognitive and communication impairments |
| Exercise session | Up to 60 minutes of individually tailored exercise including cardiovascular, balance and strengthening exercises in the large outpatient rehabilitation gym. Each participant built up gradually on all the activities in their individual circuit – initially having frequent rest breaks. Some caregivers stayed in the gym during the exercise to support and encourage their stroke participant, to discuss issues with one of the staff members or to chat to other stroke participants or caregivers; others took a break. The longer session allowed time for caregivers to walk into the town centre to shop or go to the bank. |
| Information session | 30 minutes interactive discussion in one end of outpatient rehabilitation gym. Sessions as before plus session on managing medical emergencies – what to do in the case of seizure, stroke or medical problem. Caregivers and stroke survivors participated. |
| Supporting documentation | Patient held ASPIRE card to record details about medication, risk factors, weight & blood pressure, rehabilitation goals and exercise programme. |
| Staffing | Consultant therapist – rehabilitation, Rehabilitation assistant plus Consultant nurse – Stroke |
| Timing | Thursdays 10.30 – 12 with new patient interview between 10am and 10.30am. |

PDSA 2: Study. Formal evaluation October 2007

For this second PDSA study phase, the author and her nurse consultant colleague discussed their views of how the programme was running, supported by information from the author's 'praclog', plus information from the repeat audit. This repeat of the initial local audit referred to in Table 1, was carried out in October 2007, by the audit department of the hospital. The questionnaire used, was again based on the one used in the national audit (Stroke Association, 2006), with the addition of one further question; "Have you attended the ASPIRE programme?" As in the previous audit, questionnaires were sent out to 50 consecutive discharges from the acute hospital, who had been admitted with an acute stroke after April 1st 2007. A response rate of 56% was achieved with 28 respondents returning the questionnaires, 17 of whom were male and 11 female. Table 24 shows the age distribution of the respondents.

Table 24: Age of respondents

| Age | Number of respondents | % of respondents |
|--------------|------------------------------|-------------------------|
| Less than 50 | 2 | 7% |
| 51-60 | 3 | 11% |
| 61-70 | 8 | 30% |
| 71-80 | 8 | 30% |
| 81-90 | 5 | 19% |
| Over 90 | 1 | 4% |

The follow up, received by each stroke survivor, at the time of audit, can be seen in table 25; which shows that 18 of the 28 respondents had attended the ASPIRE programme.

Table 25: Follow up after admission for acute stroke

| Type of follow up | Number of respondents | % of respondents |
|---|------------------------------|-------------------------|
| Seen by GP | 24 | 86% |
| Attended ASPIRE | 18 | 64% |
| Seen by stroke physician | 13 | 46% |
| Seen by community stroke nurse consultant | 10 | 36% |
| No follow up | 2 | 7% |

In answer to the question ‘Were you/ your carer given enough information and advice on how to prevent further strokes?’; 10 of the 13 who had attended ASPIRE said yes; whereas only 4 of the 8 who had not attended ASPIRE said yes. Clearly; although, these are very small numbers, and it is not known whether this information would lead to a reduction in further vascular events; these responses provided further encouragement to continue with the programme. Qualitative feedback from 'ASPIRE' participants in answer to the audit question; ‘What do you feel about the follow up services you have received since being discharged from hospital?’; received the following twelve positive comments:

- 1: *“Very satisfactory”*
- 2: *“Not too bad”*
- 3: *“Good”*
- 4: *“The ASPIRE programme has been very good”*
- 5: *“Follow up has been really good, still going to occupational therapy which has been excellent. Have spoken to Debbie a number of times. Thank you for all your support.”*
- 6: *“Good, especially from physiotherapists on the ASPIRE programme”*
- 7: *“Having completed the ASPIRE course it gave me a lot of information and good advice. It helped me with better movement and contact with other stroke sufferers. The additional physio has given me advice on mobility and a programme of exercises which I can continue at home. All staff have been very helpful and have been willing to be the point of contact for any health services that I have required”*
- 8: *“Excellent. I go on Thursday mornings where the atmosphere is most welcoming and the programme very informative and helpful.”*
- 9: *“Thank you. I feel very good as everyone has been very considerate and very helpful. Thanks to ASPIRE especially.”*
- 10: *“Excellent 12 week course after discharge.”*
- 11: *“The assistance I received from both X and Debbie was outstanding. Their care and consideration was a credit to them both.”*
- 12: *“I found the ASPIRE programme very helpful, I was able to meet other people who had suffered a stroke of varying degrees. The talk at the end of each session was very informative”*

There were however two less favourable comments from those who had attended the ASPIRE programme; one simply commented *“Not very happy about treatment”*. The other was from a lady who only attended four ASPIRE sessions, and at the time was on the waiting list for individual outpatient physiotherapy.

“Very poor - pain management has been difficult and appropriate physiotherapy has not been provided. The ASPIRE programme did not seem relevant - more effort should be spent on physiotherapy and everyday tasks. The impression is that the stroke follow-up in general

more towards older people - being only 43 when I had the stroke meant that some of the treatments were of little use."

Comments from two of those, who did not attend ASPIRE, give an indication of the variability in services being received at the time:

1: *"Not very good. One is left far too much to one's own devices and decisions for too long. It is both very frightening and lonely and isolating to both carers and patient - making one feel like outcasts, particularly when one is very disabled. The standards of the NHS have really slumped over the past few years and the idea of care in the community does not work because there is too much bureaucracy with too many people under the umbrella doing specialist jobs, creating lots of vacuums in the care. the 'care workers' require much better training, discipline, personal hygiene and understanding of their work to bring back a professional standard if the community care is to improve at all."*

2: *"Stroke side: dad has partial sight since his stroke. x and her colleagues have been very helpful also the physio and the occupational therapist were very helpful with very good ideas for dad. We were very happy with all the information we were given. Maybe it would be nice if they could put my dad in contact with other people with my Dad's same condition. Other than that everything has been very good."*

At this point, it seemed that for those discharged directly home after an acute stroke, and who chose to and were able to attend; the ASPIRE programme appeared to be an effective way of supporting stroke survivors to self-manage after stroke, by increasing their knowledge of secondary prevention and having positive effects on mood, confidence and participation. Notes from the author's 'praclog' indicated that, increasingly stroke survivors of different ages with a wide range of impairments, including cognitive and communication difficulties were attending, and seemed to benefit.

PDSA 2: Act

Although audit results from small numbers of participants do not provide robust evidence, the county wide stroke group gave their approval for continuation of the project. The ASPIRE programme had now become a well-established part of the local stroke pathway; however, with referrals starting to come from elsewhere in the county, the county wide stroke group started to debate how or whether to roll the programme out. Whilst continuing to deliver the ASPIRE programme for the

county, the author needed to consider how to continue to make the programme accessible to participants, with a wide range of deficits, and to manage an increasing number of referrals. In addition, feedback from participants noted in the author's 'praclog', suggested there were challenges in remembering their record card for the programme; some participants were finding parking or the start time difficult; and some of the less able were struggling with the lack of equipment and the acoustics in the large gym. These factors are discussed in the planning phase for the 3rd PDSA cycle.

4.4 PDSA cycle 3 2008 – 2009 (includes Phase 1 research, stroke survivors & caregivers)

PDSA 3: Plan

From the start of the programme, participant held record cards had been used to capture weekly weights, blood pressure, individual's goals and risk factors and details about each individual's exercise programme. Participants were encouraged to take ownership of these whilst attending ASPIRE, to increase their awareness, support their self-management and improve communication between the ASPIRE programme and others involved in their stroke management, such as GP and stroke coordinator. On discharge, these records were filed in medical notes and a summary given to the participants on discharge. Unfortunately, many participants forgot to bring their record cards with them each week, which led to challenges remembering the detail of exercise programmes. The paperwork was; therefore, redesigned, to keep a separate log of exercises with their medical notes whilst the participants held onto a record of their goals, risk factors, weights and blood pressures.

As the numbers of referrals increased, it was beginning to have a significant impact on the way the ASPIRE programme was delivered. Although the number of people referred through the local acute stroke unit remained about the same, increasingly, there were more referrals from the newly appointed local stroke coordinator and the existing community rehabilitation teams. These referrals tended to be either; those whose acute stay had been in other acute hospitals who were referred in a little later after their stroke; or those who despite a lengthy

inpatient rehabilitation phase, were still struggling with the lifestyle changes needed to reduce their risk of recurrence. There was also a small group, who were referred in predominantly for peer support; these were often those under 60, who may not have met any other younger stroke survivors during their inpatient stay. The impact of this increasing referral rate was longer delays from referral to starting ASPIRE, increasing from less than 3 weeks up to about 8 weeks or more. Participants were also travelling further, so there was more pressure on the limited parking places, and as noted in the author's 'praclog', demand to hold the session a bit later in the day.

The author discussed the issues with colleagues involved in delivering the programme and hospital managers. At the same time, there was some restructuring of the rehabilitation space, as the cardiac rehabilitation and general rehabilitation started to share the same space. Agreement was reached, to use the rehabilitation space differently, to extend the length of the session, and to provide a more relaxed environment for the interactive information session.

PDSA 3: Do

The exercise session was split into two halves, with the information session sandwiched in between. This split session; doubled capacity; prevented queuing for equipment; and allowed a later start time for those travelling further whilst still maximising the opportunities for peer support. This later start time also seemed to suit those who needed longer to get ready in the mornings; often the older participants or those relying on a care package.

The additional equipment; particularly cardiovascular equipment such as treadmills, rowing machines, and cross trainers that came with the cardiac rehabilitation team; complemented existing rehabilitation equipment, such as free weights and pulley weights stack, to give a greater range of exercise, for those with no physical impairment at all. Existing rehabilitation equipment, such as the wheelchair accessible exercise bike, parallel bars, balance equipment and arm bike, suited those with residual physical impairment. A summary of this revised intervention is given in table 26.

Table 26: ASPIRE programme 2008- 2009

| | |
|--------------------------|--|
| Name of Programme | ASPIRE |
| Assessment | Individual physical assessment of the stroke survivor and discussion with stroke survivor and carer about their time since stroke and their aims of attending the programme. Goals and exercise programme agreed. Blood pressure & weight recorded. |
| Participants | Up to 16 stroke survivors and their caregivers. Stroke survivors aged 22 - 92 and most with mild to moderate residual impairments mostly of communication, cognition, sensation or upper limb movement. A small proportion needed assistance plus a gait aid to stand and were able to take a few steps at most. |
| Exercise Session | Up to 60 minutes of individually tailored exercise including cardiovascular, balance and strengthening exercises in the large outpatient rehabilitation gym. Each participant builds up gradually on all the activities in their individual circuit – initially having frequent rest breaks. Some caregivers stayed in the gym during the exercise to support and encourage their stroke participant, to discuss issues with one of the staff members or to chat to other stroke participants or caregivers; others took a break. |
| Information Session | 30 minutes interactive information session held in corner of gym. |
| Supporting documentation | Patient held yellow ASPIRE card to record details about medication, risk factors, weight & blood pressure, recovery from stroke and secondary prevention goals plus exercise programme. |
| Staffing | Consultant therapist – rehabilitation, Rehabilitation assistant, Consultant nurse – Stroke. |
| Timing | Thursdays 10.30 – 12 with 2 new participants having initial discussion and assessment between 9.45 am and 10.30am. |

PDSA 3: Study

For this third PDSA study phase, in addition to information from the author’s ‘praclog’ and ‘doclog’; data and analysis, from interviews with patients and caregivers, for phase 1 of the research study, provided a wealth of information. Please refer to chapter 3, sections 3.7 – 3.11 for the methods related to phase 1 of the research study.

Findings phase 1 research – patients and caregivers.

Characteristics of participants

A total of sixteen stroke survivors and eight caregivers were approached by letter, to participate in the study. Of these, a high proportion (ten out of sixteen stroke survivors and seven out of eight caregivers) replied to the invitation to participate, and agreed to be interviewed. Interviews were carried out, at between 3 and 13 months after completion of ASPIRE. Seven of these interviews were with stroke survivors alone (S1, S4, S5, S7, S8, S9 and S10), and four with caregivers alone (C1, C2, C4 and C9). With the remaining couples (S2/C2, S3/C3 and S6/C6) the interviewees chose to be interviewed with both stroke survivor and carer present (see Tables 27 and 28 for the characteristics of the participants). Participant characteristics were identified through interview, and in the case of stroke survivors only, confirmed through their medical records. Caregivers' ages were not recorded; however, all were a similar age to their spouses. Pseudonyms are used to refer to the interviewees throughout the rest of this chapter in order to protect their anonymity.

Table 27: Characteristics of interviewed caregivers (phase 1)

| Inter-Viewee | Gender (M/F) | Civil status | Interviewer's view of health & activity levels (caregivers). | Time since stopped ASPIRE | Number ASPIRE sessions. |
|--------------|--------------|--|---|---------------------------|-------------------------|
| C1 Jill | F | Common law wife | Fit and well, active retired teacher. | 5 months | 12 |
| C2 Jenny | F | Married | Fit & well, retired active member of local community. | 6 months | 12 |
| C3 Stella | F | Common law wife | Fit and well. Employed part time. | 3 months | 12 |
| C4 Eileen | F | Married | Retired. Active but some health problems. Regularly looks after grandchild. | 5 months | 12 |
| C6 Jean | F | Married | Retired. Some health problems but active. | 10 months | 12 |
| C7 Brenda | F | Married & living with teenage son. Employed. | Fit and well. Employed full time. | 13 months | 12 |
| C9 Daniel | M | Married | Retired. Active though some health problems. | 9 months | 12 |

Table 28: Characteristics of interviewed stroke survivors (phase 1)

| Inter-Viewee Gender (M/F) & Age at stroke (years) | Civil & employment status at date of stroke | Risk factors & relevant past medical history | Type of stroke. Residual effects of stroke at time of attendance at ASPIRE | Time since ASPIRE at date of interview / Number of ASPIRE sessions attended |
|--|--|--|--|--|
| S1 Bob M 66 | Common law husband Working full time manual job, about to retire. | Atrial Fibrillation Hypertension Hypercholesterol-aemia | Left lacunar infarct. Reduced right hand dexterity. Right leg weakness. Mild dysphasia. Fatigue. No cognitive difficulties. | 5 months / 12 |
| S2 Jeffrey M 74 | Married Retired | Previous lacunar infarct. Low physical activity levels Increased alcohol intake | Left parietal infarct. Unsteady on feet. Dysarthria. Fatigue. Low mood. Memory, attention & concentration difficulties. | 6 months / 12 |
| S3 Bill M 53 | Common law husband. Self-employed sculptor. | Stress Poor diet Smoking | Reduced sensation, dexterity, coordination in right hand. Unsteady on feet. Low mood, anger. Planning, attention & concentration difficulties | 3 months / 12 |
| S4 Jim M 83 | Married Retired | Ischaemic Heart disease. Previous Myocardial infarction Previous TIA Increased alcohol intake. Low physical activity levels Hypertension | Right basal ganglia & parietal infarct. Unsteadiness and difficulty walking. Left hand weakness Dysarthria. Low mood. Fatigue. | 5 months / 12 |
| S5 Harry M 71 | Widowed Retired from desk job | Hypertension | Left parietal infarct. Dysphasia, reduced balance and upper limb dexterity. Memory difficulties. | 9 months / 14 |
| S6 Paul M 76 | Married Retired cashier clerk. | Atrial Fibrillation | Left Partial anterior circulation infarct. Dysarthria, right arm weakness & sensory loss. Fatigue. Right hemianopia. No cognitive difficulties. | 10 months / 12 |

| Inter-Viewee Gender (M/F) & Age at stroke (years) | Civil & employment status at date of stroke | Risk factors & relevant past medical history | Type of stroke. Residual effects of stroke at time of attendance at ASPIRE | Time since ASPIRE at date of interview / Number of ASPIRE sessions attended |
|--|--|---|---|--|
| S7 Matt M 46 | Married & living with teenage son. Employed as engineer. | Type 2 diabetes Hypertension Stress Hypercholesterol aemia Poor diet Overweight Lack of physical activity Previous TIA | Left parietal infarct. Reduced balance, coordination and upper limb function. No communication or cognitive difficulties. | 7 months / 12 |
| S8 Leo M 71 | Widowed Working part time driving for concrete company. Stonemason by trade. | Overweight Poor diet Hypercholesterol aemia Hypertension Lack of physical activity Previous left lacunar infarct. | Left temporal infarct. Dysarthria and some residual right upper limb functional problems. No cognitive difficulties | 9 months / 12 |
| S9 Mary F 70 | Married Retired | Type 2 diabetes Hypertension Hypercholesterol aemia Poor diet Overweight Lack of physical activity | Left frontal infarct. Mild dysarthria, dysphasia and slight right arm and leg weakness. | 9 months/ 12 |
| S10 Sheila F76 | Widowed Retired | Lack of physical activity Previous myocardial infarction Increased alcohol intake. | Right Middle cerebral artery infarct. Dysarthria, reduced balance and coordination. Anxious & low in mood. Some short term memory. Mild expressive dysphasia. | 12 months/ 12 |

The key themes and sub-themes, in terms of outcomes and processes, that were identified through thematic analysis, of the interviews with stroke survivors and caregivers, are summarised in table 29 then discussed in detail below. The words of the interviewees themselves are powerful, so are used to illustrate these themes.

Table 29: ASPIRE programme impact: themes and sub-themes.

| Themes | Sub-themes – outcomes | Sub-themes – processes |
|---|--|---|
| A life I like: the confidence to do the everyday activities important to a person after a stroke | <ul style="list-style-type: none"> • Increased confidence | <ul style="list-style-type: none"> • Goal setting & measuring progress • Reassurance • Feedback • Motivation • Comparison with others • Encouragement from staff • Positive attitude |
| Changing hearts and minds: the confidence, knowledge and health behaviour change to reduce vascular risk after stroke | <ul style="list-style-type: none"> • Increased self-efficacy (knowledge, skills & confidence) – stroke survivors & caregivers • Behaviour change | <ul style="list-style-type: none"> • Behaviour change • Social support |
| In the same boat: the benefits of peer support for stroke survivors and caregivers | <ul style="list-style-type: none"> • Improved mood • Relief from caregiving | <ul style="list-style-type: none"> • Structure & stability • Empathy & peer support • Reduced isolation, increased social support |

Theme 1: “A life I like” – confidence to do everyday activities

Probably the most important theme from the individual stroke survivors’ perspective was; “A life I like”, which referred to the impact of the ASPIRE programme, on recovery and rehabilitation after stroke. As outlined in table 29, there were several interconnecting sub-themes, including **comparison with others** which is illustrated by the following comment (lines 203-5) from Mary;

“and when you see other people there as well, I mean they were all a lot worse than I was, but you could see them sort of progressing and that, it is helpful, definitely.”

It was not only the peer comparison, but also **encouragement from staff**, that made the difference as Paul explained (lines 119 -122);

“It was certainly a confidence booster. Being round people you could compare and you got the encouragement from any of the staff there.”

A culture that supported a **positive attitude** was identified as a further vital element in recovery and rehabilitation, which enabled respondents to live a life they liked, and was demonstrated by couple Bob and Jill. Bob said (lines 63 -66);

“I’ve got so many things I wanted to do and it hits you, you’ve got this stroke and you think; ‘Can I do them?’ And one side of your brain thinks; ‘no you can’t’ and the other side of your brain says ‘you will do them’, and that’s what drives you on”.

This **positive attitude** was mirrored by his partner; Jill (lines 136 -138);

“Everything will take him longer, you know but he achieves wonderful results so I just think he needs a lot of encouragement, and if he gets the encouragement and the praise then he wants to do more. And I think it’s practice, it’s just to go on doing those things isn’t it?”

Despite the encouraging approach by Jill, Bob clearly still also appreciated the **encouragement from staff** (lines 74 -78);

“I think the ASPIRE group helped me, give me confidence by saying things like you will do these things, you will get better. That was the reinforcing part of it, somebody being encouraging and saying you know...somebody....I mean your wife can be encouraging and say you things that....she doesn’t really know. But you get somebody who is in the know and when they say you WILL recover, you tend to rely on that and trust them, and sure enough, you do..... the physiotherapist and the nurses down at ASPIRE. They know about strokes and they can drive a person onto, onto later recovery.”

Increased confidence was central to this first theme, as Bob simply put it (line 101); *“I got more confidence actually.”* Mary went into more detail about how **increased confidence** impacted on both her and her husbands’ lives (lines 101 – 106 & 109-110);

“I thought it was brilliant. It gave me confidence, a lot of confidence because at first I didn’t want (husband) to go out - I mean he didn’t play golf for quite a few months afterwards. And I didn’t want him to go out anywhere without me because I was frightened of it happening again. Every time if you got a little twinge anywhere, that when am I going to have another one? But it just – it got me into exercise for one thing and it gave me so much confidence that gradually this fear just went and I’m fine. I would say it was one of the most important things that could have happened. Yeah I don’t think I would have gained the confidence, perhaps eventually I might have done but not as quickly.”

Not all interviewees made a full recovery, and despite **increased confidence**, had to acknowledge their limitations as Bob explained (lines 163 – 168);

“I get more confident in the things that I do. I’m still wobbly on my legs of course and I still have to stop when these people rushing about but I fear if they bump into me or get out, I’ll fall over. So you have to just watch and wait until they stop rushing around and then you can make your move. Yes I’m still not certain of my legs, no I’m still not certain. Same as my hand,

I'm not certain of my hand. I mean I can make a cup of tea, I can boil the kettle and you've got to be really, really careful when you do it, but you can do it."

Attendance at ASPIRE gave people **reassurance**; helped people to have a sense of future and hope; supported them by giving **feedback**; and enabled them to measure progress and set realistic goals, as Bill said;

"It's made things clearer in terms of what my goals should be and also not to expect as much, to take it slowly and steadily rather than expecting to, you know, do a few exercises and I'm back to normal."

Some participants, whilst being encouraged towards self-management of their rehabilitation, clearly benefited from the weekly attendance at ASPIRE, to provide some **motivation** as Matt explained (line 233 – 237);

"You're trying to overcome, in my case, a fairly, a fairly minor disability, that's made quite a large impact – I can't drive at this stage, I can't write properly and you know the little bits of progress that you make – it's like the teacher with a giving a boy a sweetie, or whatever animal you give carrots to encourage them. I respond well to a pat on the head."

Jeffrey, who also initially found attending each week, helped his **motivation** (line 117); *"Well it made me do things. It made me take exercise"*; was continuing to exercise regularly 6 months after finishing ASPIRE (lines 121 & 125);

"Now I go for the paper once a day. In the morning. And twice a week I go and do physical jerks in the local, in the school."

Despite encouragement from family and friends; however, not everyone was able to continue to progress after completing the ASPIRE programme, as Jim explained, he lost confidence (lines 183-6 & 211-6);

"Well coming to the programme was very beneficial I thought. And I was able to do things there physically that I can't do now. I've retrogressed. Initially I was able to.... really, really well do what I was before....but I can't now. I mean, it's not very far up to this end of town, and I was walking up there to pick up the papers in the morning, but I can't do that now. It didn't happen overnight. It's just a feeling of great insecurity. And apparently physical restriction, it wasn't painful physically."

Jim, despite benefiting whilst attending, appeared to be reliant on the weekly encouragement from others, rather than internalising the process of self-management. As he had not embedded self-management into his own life, it appeared that gradually once he had finished the programme, he lost momentum.

In hindsight it would have been helpful to explore this further in the interview; was this due to something about the way the ASPIRE programme was delivered? Or perhaps Jim was not yet at a stage to take charge of his own stroke recovery. By the time most interviewees had completed the ASPIRE programme; however, the support and motivation had enabled them not only to self-manage rehabilitation, in order to live a life they liked, but also supported health behaviour change, which was the next identified theme.

Theme 2: “Changing hearts and minds” – health behaviour change to reduce vascular risk

The second theme is “Changing hearts and minds”. ‘Changing minds’ because of the gains in knowledge; ‘Changing hearts’ because participants felt they had the ability to do something with that increased knowledge. This aspect was probably the most significant from society’s perspective, as it highlights the impact of the ASPIRE programme on vascular risk reduction after stroke. Interviews with participants suggested that, in addition to the increased confidence already discussed, the ASPIRE programme had a positive impact on both caregivers’ and stroke survivors’ **self-efficacy**, through increasing their knowledge about stroke and vascular risk. As Jill explained (lines 67-8); *“I’ve gained most of the knowledge through the ASPIRE group.”*

That increased knowledge was still evident in most of those interviewed, even several months after completing the ASPIRE programme; Bob was aware that (lines 9 – 10);

“Well in my caseI had this atrial fibrillation. This irregular heartbeatand that, that I think brought on my stroke. That’s what caused it.”

Bill (lines 49 – 50) knew that his stroke was caused by;

“....a clot in the carotid artery. It went to my brain and stuck somewhere and cut off the all the supply of blood to that part of the brain and killed all the cells.” Caregivers had also retained their knowledge as Jill illustrated (lines 53 & 56); *“he was put on Warfarin. That was to keep the blood thin. To thin the blood or stop it from clotting”.*

Increases in knowledge although important, are only the first stage in **health behaviour change**; implementing changes in behaviour has to follow. Harry,

interviewed several months after completing ASPIRE, identified how he had incorporated the advice given during the information sessions, into his daily routine (lines 249 – 254);

“ The need to exercise was one, and I have been more aware since, in the last while, I now live that much nearer town so I do, take a longer walk round than the absolute necessary, the necessary walk of going, because I collect a paper each morning so that I’ve always got to go out for my paper, but now, as often as not, when the weather’s reasonable and that sort of thing, I will walk the slightly longer way, which does involve the little hill”.

Some participants’ health **behaviour changes** had directly led to measurable health improvements, as reported by interviewees. Bill referred to his previous eating habits (line 5): *“at night, stuff my face full of biscuits”* and his partner Stella also reported (line 327) *“When I first met him it was five Mars bars at a time. I mean you can’t believe it, honestly”*. This was a marked contrast to the changes in behaviour after the ASPIRE programme, summarised by Bill in the following excerpts from his interview (lines 303-5, 297-8, 310 -5 & 319 - 20);

“Well I was absolutely gobsmacked when I went to see the doctor and he gave me the results of the blood tests (for cholesterol) and he just went 3.7 - it’s just amazing. I was thinking well I hope I’ve got it down a bit, you know. You know I was glad to get that down I managed to cut the medication from 40 to 20 mg. Now I actually find the low fat or healthy eating is not bland it actually enables you to you taste the individual item on your dinner plate rather than having it swamped in salt and gravy. I still enjoy the old chocolate and stuff but I’m being more balanced with it.”

For most interviewees, the increased self-efficacy led to health **behaviour change**, that continued long after attendance at ASPIRE finished. Sheila talked about her fitness levels before her stroke (lines 172 – 175);

“so if I wanted anything you know, I, it would just be a case of getting in my car. The only walking that I did was round to the post box or across to my neighbour over the other side of the road. I could have kept more fit.”

Sheila was interviewed one year after completing ASPIRE and demonstrated quite marked and lasting health **behaviour change** (lines 92 – 96 & 150 – 152);

“Simply because, I am, thanks to the 3 months at the gym after my stroke at the hospital which I thought was absolutely marvellous and I’ve joined a gym which is just over the road from me, so I walk to it. I walk down to the town and there’s a climb back, I confess I have to stop a couple of times but it’s jolly good for me and I consider I’m fitter now than I was

before my stroke. I think I'm doing pretty well. I use the stairs as often as I can. I make a point of rarely using the cloakroom downstairs. I'd rather go upstairs and use my lavatory upstairs to make sure I keep climbing the stairs."

Mary was another interviewee who made a number of significant lifestyle **behaviour changes** after her stroke (lines 190 -4, 123-30, 132- 6 & 145-6);

"We wouldn't have been going to the gym... if I hadn't had the stroke and we certainly wouldn't have joined the bowls. And as I say we used to go most places by car, we didn't walk very far at all. We do do a lot more walking so yeah it's great. It's great because last week we went to EdinburghI had been a bit concerned about the walking because I know that Edinburgh is quite hilly and somebody had told me about all the steps you have to go up and that and I was a bit concerned. But it was no problem – we walked and walked and walked on the Monday.....But it was absolutely fine, it made a terrific difference, I can walk now and you know for.... As I say we did a tremendous amount of walking which I wouldn't have been able to have done before. Since I had my stroke I've lost practically two stone, about a pound under two stone. I fluctuated quite a bit during the ASPIRE programme. I did start to go down and then seemed to put it on again. I lost just a little bit. But since we've been dieting and both of us have lost quite a bit. I mean we've changed our diet because I was never a vegetable eater, I didn't like veg but now I do eat a lot of vegetables, we eat a lot more fruit."

What is unclear is whether attending the ASPIRE programme made a difference, or whether Mary would have made the changes anyway after her stroke, as she said (lines 156-7);

"As I say it was a real wake up call. I don't want to have another one because I probably wouldn't be as lucky next time and I've just taken it as a wakeup call".

It is clear that increased knowledge and task mastery through attendance at the ASPIRE programme increased Mary's **self-efficacy** and **behaviour change** (lines 114-5 & 197 - 203);

"Because you told me exercise was important and after doing that down there for 12 weeks then we started going to the gym afterwards straightaway....I just think ASPIRE was brilliant and all the staff there I mean you were all so helpful and so friendly you just give everybody confidence. And that, the talks afterwards as well, it really did help"

The importance of caregivers, as well as stroke survivors, attending the stroke information sessions, during the ASPIRE programme, was demonstrated by married couple Jeffrey and Jenny: Jeffrey commented (lines 201 – 203);

“My wife doesn’t let me drink so much. I don’t know whether that does me good or doesn’t. But I obey her, I can’t think why, but I do!”

An explanation for this obedience came from Jenny who said (lines 199 – 203);

“I got lots of benefit from that, I was very interested in how many units of alcohol he should drink and what should be his diet and you know about the pills and that, I was interested. It gave me a bit of confidence and a bit of ammunition”.

Jenny also described how she had found a way of getting her husband to do more exercise (lines 260 – 6);

“I very cruelly and fairly recently started refusing to get one of his newspapers, I get one, so that he’s got one to, you know, have with his cup of coffee, but he likes two and so I refuse to get it so he has to”.

Not everyone interviewed was confident that they were able to reduce their risk of stroke; as Bill said (line 159); *“Not 50:50. I wouldn’t say I was that keen. I worry.”* In addition, not everyone was able to instigate health behaviour changes, despite finding the ASPIRE information sessions useful at the time, as Matt explained (lines 260 – 265);

“My personal thoughts about that is that I might find it useful to do a lot of those again. I’m not sure they’ve made a big difference to my lifestyle but it’s, they’re not rocket science, they’re things that are quite often common sense, but it’s a bit like reading a technical manual – you may have browsed through them all, you’ve seen the chapters and got the highlights and you could do with revisiting, just a refresher to reinforce.”

The importance of **social support**, widely recognised in the literature as key in changing health behaviours, was also identified by a number of those stroke survivors interviewed; as Bob said (line 44); *“Well I was fortunate because I’ve got a good wife to look after me”*; and Bill talking about the reduction in his cholesterol levels acknowledged (lines 307-8);

“Yeah that was a hell of an achievement. I couldn’t have done that without (partner), she was really helpful”.

Many people after stroke find that their social network decreases; however, one interviewee Sheila directly attributed an increase in her **social support** network to attending ASPIRE (lines 191 – 202);

“I put that down to ASPIRE again because my daughter, is a very outgoing person and you know we would come away from there and I would say what lovely people and she would say, people are lovely mother

and but I'd so shut myself away I think, I didn't mix easily, I, I've probably said before, I have an unfortunate manner and put peoples' backs up, so I tended to not mix and I'm not that good at it now actually, but I have improved – I joined the mothers' union. But er, it's nice to walk through the town and see familiar faces. I've got a friend just around the corner and she comes roundI have mixed more now, so yes, yes, it's helped."

For this participant who had longstanding difficulties with socialising, being thrown into a situation where others had a whole range of difficulties, so that she did not feel like the 'odd one out', and where she also had support from her daughter, supported her to make changes to this aspect of her life.

In addition to the role of **social support** in supporting health behaviour change, the crucial role of peer support, for stroke survivors and caregivers, arose as a theme in itself.

Theme 3: "In the same boat" – the impact of peer support

The third and final theme is "In the same boat". Peer support was found to underpin the ASPIRE programme and provided structure, stability, empathy, reduced isolation and relief from the caregiving role. Jill (lines 62-3) talked about the **structure** of the programme;

"And each week it is a very structured group because each week there's a different theme tackled."

Jill also highlighted the **stability** and **peer support** that the programme brought for stroke survivor and carer (lines 70-71 & 76-80);

"Yes and the fact that we had a regular meeting to go to when everything was very hard work and not normal. We had a point of contact once a week. And I remember one week we couldn't go and we rang up hoping that maybe somebody could offer us some transport but that wasn't possible though we did manage to take the bus even though we got there halfway through least we arrived. Although he said that after being on the bus he said it was an ordeal for him in his state and he said I'm not going into the hospital. I'm not going in. And I said well I need to go in there so we did eventually go in. The moment he walked into the gym, he was all smiles."

The benefits of peer support, such as reduced loneliness and depression plus increased understanding of stroke and timeframes for recovery, are increasingly

well recognised (Morris & Morris, 2012; Kessler et al, 2014). Bill explained clearly how the **peer support** helped him (lines 103 -111);

“It’s just that I think from an emotional point of view and reinforcing and confirming where you are the chatting with other stroke, not victims....Survivors. You know it helped on an emotional level to pick you up, make you feel right, you know. Where you were doubting what you were feeling, having it confirmed by somebody else sort of reinforced it a bit for you or the way they described it, probably in a slightly different way than you yourself would, oh, I don’t know it’d put a different angle on it which enabled you to think through it a bit better.”

Brenda also explained how she felt her partner benefited from the **peer support** of the ASPIRE programme, more from the perspective of continuity of relationships, rather than a health need (lines 188 – 192);

“It would have been really bad to just go home and not have anything I think, that was one thing. So there was sort of continuing support because he was still quite poorly then and needed I think somebody to look at him say once a week just for blood pressure and stuff. Maybe medically he didn’t but I think it does them good to just have that sort of continuity there.”

The relationships that developed between participants **reduced isolation**, as illustrated by the following quote from stroke survivor Matt (lines 250 – 251);

“It’s a point of contact really, you’re not sitting there ... you’re not sitting there isolated.”

For carer Jenny, attendance at the ASPIRE group provided not only less isolation but also some **relief from the burden of caregiving** (lines 152-153);

“I didn’t have to be here seven days and seven nights without any respite and with a very, very grumpy old thing, who wouldn’t do anything I said”.

Not everyone benefited directly from the peer support however, as Harry explained (lines 280 – 295);

“I didn’t. And that would be down to my weaknesses, not other people’s. I’m not the greatest of communicators, it’s funny, I’ve, I’m talking to you nineteen to the dozen and I get on fine on a one to one, I’ve got you know, I’ve got good friends but I’ve noticed that in groups I don’t mix very well, you know even if we’re having like a social meeting and I’m, I find, one thing, my hearing’s not very good and that’s maybe partly the reason but I tend to find that I’m on an edge of a group, I mean I could see, pick up that I was not, you know I mean I never got friendly with any of them, yeah you pass a comment, but yeah I could see that other people were far more active with each other, and building each other up, but I was... I wasn’t

.... I mean at the very early weeks you know, people I noticed that people when I first joined that they looked upon it as a club, a social activity. I'm, I didn't get that feeling but that would be because of my own weaknesses of sociability, you know, it certainly wasn't the fault of other people or the instructors or this sort of thing. It would be my reluctance to get ... you know I didn't get any benefit from interactive which I'm sure a lot of people would have done."

PDSA 3: Act

The patient and caregivers interviewees, for phase 1 of the research, were likely to present a skewed view point, as they had all completed ASPIRE, or were involved in delivering it, so could be viewed as favourably disposed towards the programme. These interviewees provided some reassurance about the way the programme was being run and also provided ideas for change. This included additional equipment to support rehabilitation of hand dexterity, or equipment required to meet an individual's particular rehabilitation needs. This was prompted by Bob (lines 111-122);

"I think as regards, I think what I'd change I think, not so much change I think, yes, maybe so, was to channel each individual needs. I mean we're all individuals, in some their hands are not right, and feet and speech and so on, and rather than put everybody on the treadmill, and everybody on the rowing machine, those that need it should be on those and those that have got hands they can't use, more, there must be more exercises to do with the hands. Rather than. I mean, you can go on the rowing machine until kingdom come but your hand is still not as it should be. That's what personally I wanted, was something to improve my hand. There was yes. I mean you could use the walking stick, picking things out of the tub, and there must be some other things that you can use. I don't know what they are, but there must be some things."

During his interview Matt wondered about the frequency of the programme (lines 290 – 292);

".... the only thing I can think of at the moment is whether I would have, could have gone down there more than once a week but that's really just to use the equipment facilities."

As a result, those participants felt by the author to be safe to use the gym equipment unsupervised, are given the option of attending the open gym sessions at the hospital, alongside other physiotherapy patients and staff.

The information session was moved into a seminar room, that now led directly from the gym and had relaxed seating, hot drink making facilities and much better acoustics thereby reducing interruptions and improving the ability of all participants to hear; an issue identified by Harry (line 285); *“my hearing’s not very good”*. With double doors between the gym and the seminar room left open, this allowed greater opportunity for peer and professional support for caregivers, whilst still being available for the stroke survivors. The aim is that those facilitating the sessions should keep the sessions interactive, flexible and responsive. This can be quite challenging; however, as not everyone is a ‘group’ person and many people prefer just to listen, so although the information sessions are interactive, staff members do not insist on participation. As Jeffrey said (line 134); *“I didn’t talk much. Other people did.”* Different participants get something different from the information sessions so a broad range of topics are included. As Mary said (lines 138 -9);

“A lot of them say with finances and that sort of thing didn’t apply to us, but it was interesting to know what’s there anyway and what people can do”.

It is increasingly recognised that group-based interventions are not accessible or appealing for all, tending to attract the better educated, more activated and more effective self-managers (Ahmad et al, 2014). As social inequalities are an important contributor to low activation and long term conditions (Hibbard & Gilbert, 2014), group-based self-management interventions may under serve those who need them most, unless they have a strong individually tailored component (Ahmad et all, 2014).

A comment made by one of the caregivers, Jill, noted in the author’s ‘praclog’, was that although it was helpful, to have time away from their stroke survivor during ASPIRE, to go to the bank or other essential activities like a visit to the dentist, she found it difficult to plan around the most helpful information session. Modifications were made to the content and layout of the participant held record, to enable participants to know what information sessions were planned for each week. Other changes made, due to informal feedback from participants noted in the author’s ‘praclog’, included provision of a water fountain by the gym, and also lockers and coat hooks for participants’ belongings. Moving to the informal seating area allowed tea and coffee, rather than just water, to be served. This led

to one participant, who had just finished the ASPIRE programme, volunteering to make the hot drinks, which freed up staff to help the less mobile patients through from the gym. This volunteer also gave her own views and experiences of life after ASPIRE, during the information sessions, which helped give participants an idea of the future.

As the author noted in her 'praclog', this extended the existing process of more experienced participants, giving support and encouragement to newer starters. Soon afterwards, another participant, who before her stroke had been employed in a works canteen, despite being well beyond retirement age, offered to help the other volunteer, with making refreshments. It became apparent that the kitchen was too small for two people, so the first volunteer agreed to help out during the exercise session by being available to talk to participants and share her experiences. It is known that the benefits of peer support extend to those giving as well as receiving support (Morris & Morris, 2012). The author noted in her 'praclog' how much benefit both these volunteers gained, as well as gave.

As not all interviewees mentioned the goals they set at the start of the ASPIRE programme, the author wondered how relevant they were and whether participants had achieved, exceeded or changed their goals, or needed additional encouragement or information to support them.

4.5 PDSA cycle 4; 2009 – 2010 (includes Phase 1 staff & volunteers)

PDSA 4: Plan

A process for vetting, inducting and making use of past participants as volunteers, was agreed with the hospital volunteer coordinator. A balance trainer was bought, to allow those who were less steady on their feet, to retrain their balance more independently. Funding for this large piece of equipment was granted by the hospital League of Friends, after the author had successfully presented a case for funding support, to the hospital medical devices committee (see appendix 11). An informal goals review was planned for each participant half way through their programme, to provide an opportunity to adjust goals and support provided, as needed.

PDSA 4: Do

A summary of the revised programme is given in table 30.

Table 30: ASPIRE programme 2010

| | |
|--------------------------|--|
| Name of Programme | ASPIRE |
| Assessment | Individual physical assessment of the stroke survivor and discussion with stroke survivor and carer about their time since stroke and their aims of attending the programme. Goals and exercise programme agreed. Half-way goals review instigated. Blood pressure & weight recorded. |
| Participants | Up to 16 stroke survivors and their caregivers. Stroke survivors aged 22 - 92 and most with mild to moderate residual impairments mostly of communication, cognition, sensation or upper limb movement. A small proportion needed assistance plus a gait aid to stand and were able to take a few steps at most. |
| Exercise Session | Up to 60 minutes of individually tailored exercise including cardiovascular, balance and strengthening exercises in the large outpatient rehabilitation gym. Session supported by volunteers. Each participant builds up gradually on all the activities in their individual circuit – initially having frequent rest breaks. Some caregivers stayed during the exercise to support and encourage their stroke participant, to discuss issues with one of the staff members or to chat to other stroke participants or caregivers; others took a break. |
| Information Session | 30 minutes interactive discussion in seminar room – informal seating area. Tea and coffee served by volunteer – dysphasic ex-ASPIRE participant. Information sessions as before though with increasing involvement of volunteers. |
| Supporting documentation | Patient held yellow ASPIRE card to record details about medication, risk factors, weight & blood pressure, recovery from stroke and secondary prevention goals plus exercise programme. |
| Staffing | Consultant therapist – rehabilitation, Rehabilitation assistant, Consultant nurse – Stroke plus 2 volunteers |
| Timing | Thursdays 10.30 – 12 with 2 new participants having initial discussion and assessment between 9.45 am and 10.30am. |

PDSA 4: study

For this fourth PDSA study phase, in addition to information from the author's 'praclog', 'doclog' and interviews with previous staff and volunteers in phase 1 of the research study; the author sought the views of colleagues and volunteers, currently involved in running the programme, as to changes needed. The methods for this study can be found in chapter 3, section 3.12.

Findings phase 1 research – staff and volunteers.

Seven, of the nine staff and volunteers at that time, agreed to be interviewed, the other two did not reply despite a reminder. Table 31 gives details of the backgrounds and involvement in the ASPIRE programme, of those that were interviewed. The occupational therapist and pharmacist, who each led a 30 minute information session every 12 weeks, were the non-respondents.

Table 31: Staff including volunteers interviewed

| Interviewee | Profession / job role | Involvement with ASPIRE |
|-----------------|---|--|
| P1 Charlotte | Consultant nurse - acute stroke. Prescriber. | Jointly involved with the author in the initial planning and development of ASPIRE. Involved with delivery of ASPIRE for more than 3 years Individual advice, information provision and support for participants and caregivers provided during exercise session. Identification & follow up of medical aspects including investigation results, medication issues and changes in health status. Leading information sessions on topics such as relationships. Encouraging, organising & training ASPIRE participants to become volunteers with the stroke service. |
| P2 Karen | Finance & benefits officer | Leading information session once every 12 weeks for 3 years on sources of support especially financial. |
| P3 Lily | Dietician | Leading information session once every 12 weeks for 3 years on healthy eating |
| P4 Kate | Rehabilitation assistant | Experienced rehabilitation assistant involved every week for just over a year. Assisting and progressing exercise programmes. Individual advice, information provision and support for participants and caregivers provided during exercise session. |
| P5 Diana | Rehabilitation assistant | New rehabilitation assistant involved every week for several months at date of interview. Preparing equipment and information for ASPIRE programme. Trained to take weights and blood pressures and assist and progress exercise programmes. Interacting with participants and caregivers during exercise |
| P6 Dave | Male volunteer | Ex-ASPIRE participant and regular gym user. Attended trust induction programme. Encouragement and support for participants and caregivers during exercise. Active participant sharing experiences of life after stroke and leads the information session on holidays. Supports current inpatients. |
| P7 Sue | Female volunteer | Ex-ASPIRE participant and keen walker. Attended trust induction programme. Encouragement and support for participants and caregivers during exercise. Active participant sharing experiences of life after stroke in information sessions. Supports current inpatients. |

Findings - Staff views of the ASPIRE programme's impact on participants

The interviews, with paid staff and volunteers, provided a variety of perspectives, on the impact of the programme on participants. All interviewees were encouraged to speak freely; however, they may have felt unable to fully give their opinions, as the author as the interviewer, is a senior member of staff. This may have influenced the opinions they gave. From notes in the authors 'doclog', the majority of interviewees were enthusiastic, and appeared to feel a sense of ownership over the development of ASPIRE. Overall there was a great deal of consensus, between the participants' and staff's views, of the impact of the ASPIRE programme on participants, with both groups citing increases in confidence and mood.

A number of the staff interviewed highlighted that these findings did not apply equally to all participants, as some appeared to benefit more from attendance at the ASPIRE programme than others. Volunteer Dave, who had helped with the ASPIRE programme for over a year, offered his perspective on this. He felt that some participants were more committed to progress than others (lines 25-7);

"You know the people that really want to come in, and have a target and a goal to improve themselves will come no matter what the weathers like and no matter how they feel."

A further aspect, in which staff did not agree fully with the findings from phase 1, was in relation to the impact of knowledge. Although all the participants interviewed for phase 1 were positive about the gains in knowledge made, some staff's views were that not everyone attending the ASPIRE programme was ready, willing or able to absorb the information; as Kate astutely commented (lines 17-22);

"I think for people who really want to take that knowledge on they do and they take it on in a very good way but for people who haven't exactly accepted what's happened to them in the full sense then they don't tend to take on the full sort of package that can be offered. But for the people who do I think that they learn a lot about blood pressure and just the simple things that they can keep an eye on and sort of going to their GP and monitoring those sort of things, I think that from that they get to know all about that and they can take that away with them."

Organisation and logistics

From the start, there had been discussion about where is the best location to hold the ASPIRE programme, as Charlotte explained (lines 52 – 65);

“I think the other thing I constantly question is where the classes should be held and your gut feel is the fact that these, they should be held in a community setting because you’re wanting to promote that transition into independence however the more that the clinic goes on, the more I change my mind on that and I think that’s not only from a medical perspective of if people are unwell, we’ve got all of the facilities on hand but a lot of the patients like the reassurance to begin with of being in a familiar environment. And again it’s not uncommon for staff from the ward to come down and see them and that’s very good from a morale point of view for the staff. I think the other thing from a logistical point of view with the secondary prevention talks, one of its strengths is that the people presenting are different most weeks and if it were to be held in a church hall then there would be problems of actually enabling staff to be released to travel across town for a half an hour teaching session so by default you would be narrowing your group of experts which I think would be detrimental because while we can talk about diet the fact that the dietician comes and has the skills to go off in a tangent about a specific issue that may crop up I think that that’s very positive.”

Charlotte’s views were probably influenced by a political drive towards care being closer to home. Increasingly there is recognition that not only person-centred, but also community-centred, approaches can improve outcomes for individuals and communities (Wood et al, 2016). As the author’s hospital is the hospital for the local urban and surrounding rural community, it could be argued that it is an ideal location from which to develop a community centred approach. Volunteer Dave described where he felt the ASPIRE programme should be held (lines 242-3);

“The gym needs to have the equipment and you need a room you can sit down in afterwards and have a group talk.”

When asked whether it needed to be held in a hospital, volunteer Dave replied (lines 272-3);

“No, not really as long as one or two nurses are there and a therapist are there. We do need someone to actually take charge of it.”

Every effort has been made to run the ASPIRE programme, every week, throughout the year, and rarely cancel, in order to provide continuity, as volunteer Dave explained (lines 16-18);

“I really think everyone mostly enjoys having something they can go to every single week, and know that there are other people in the same position as them.”

In terms of timing, it was felt that participants should start the ASPIRE programme, as soon as possible, as volunteer Sue explained (lines 194-5);

“I think it is important that it is done quite soon. I think the follow-up should be done sooner rather than later.”

At their first session, goals or plans for attending ASPIRE are discussed. Dave (lines 90-91 and 24-27) stressed how important he feels this is:

“I think it is all in their attitude and in their goals and targets in what they want to get out of it. You can tell some people really want to get a lot out of it. Those who don't benefit, to be honest are those which don't have goals and targets and those that do not really want to get better. You know the people that really want to come in, and have a target and a goal to improve themselves will come no matter what the weathers like and no matter how they feel.”

The rolling recruitment to the group, means that participants seem less likely to feel a sense of abandonment, already identified as an issue for stroke survivors and caregivers (Stroke Association, 2006; 2012), once their time at the ASPIRE programme is over. Most recognise that their time with the group has a limited lifespan, and that there is a time to move on. Volunteer Sue helps to instil that attitude in participants (lines 185-6);

“I think we all need the 12 weeks, not any shorter or longer. You have to understand that you have to get on with your life after ASPIRE you know”. Diana agrees, that twelve sessions, seems to be about the right length of time, for people to attend the ASPIRE programme (lines 232- 6);

“I think the length of time is a good length of time because it does give ... it's long enough for people to change through, to understand a bit more, to learn a bit more. It gives them the opportunity to ... you know if you shorten it too much and maybe they're a bit nervous the first couple of weeks and don't really want to ask the questions. They get to know everyone I think and a bit more ... I think the time's right.”

Being part of a group

Each week, whilst waiting for their initial pre-exercise check, a small queue forms, which gives participants chance to chat to each other, and gives people the opportunity to bond as a group; as Diana explained (lines 107-109);

“I think it’s pretty good the way everyone comes in and they can sit and chat waiting for weights and blood pressures and things and then they can either go off together or they can work individually dependent on how they’re feeling”.

This feeling of belonging to a group is important, as Kate explained (lines 8 – 10);

“I think we support them, we offer them friendships amongst people in the group, companions who they can gain information off of, and get to know one other and get to know how each other deal with the situation.”

All staff and volunteers, recognise the need, to maximise the effectiveness of the group interactions (Carson & Hopkinson, 2005) which are fundamental to the ASPIRE programme. Volunteer Sue explained this further (lines 20-6);

“For people who have had a stroke, it is just amazing to be able to come in to a group who have obviously had similar problems or a similar type of stroke. You just feel part of a bond there because you don’t feel so alone, or shy.”

The exercise session

The exercise programmes are individually tailored; participants are shown how to use the machines; taught how to monitor their progress and fatigue levels; and participants are encouraged to take control of the programme. Participating in exercise is an important part of the ASPIRE programme; as rehabilitation assistant Kate commented (lines 25 – 27);

“obviously with regards to the exercise that sort of helps them out a lot - just gets them a little bit fitter and feels a lot more confident about sort of daily lives and just sort of getting on with things.”

The atmosphere, during the exercise session, is apparently very informal. All participants are encouraged to pace themselves, resting if needed, and are shown where the toilet and water fountain are. As Charlotte explained (lines 45 – 51);

“I think one of the biggest successes is the perception that it is very informal. I think that is probably an incorrect perception but that said I know when the group was first started it followed a much more cardiac rehab ethos whereby there was a timer and people went from one piece of equipment to the other and that didn’t seem to flow so that would be one of the first recommendations is the fact that people do have their own individual exercise programme and if people don’t feel that they want to go straight from one bit of equipment to another then that’s absolutely fine.”

This relaxed atmosphere, gives participants the chance to talk to each other and share experiences; as Diana explained (lines 100-104);

“There’s no-one beside them saying you must do 10 minutes on the treadmill – it’s not so much like an appointment based, where you say this is what we’re going to do today. They’re, because they’ve got the freedom to do as little or as much exercise as they want. I think whilst they’re in the gym they’ve got plenty of opportunity to chat as well as whilst they’re in having a cup of tea afterwards.”

This may sound very informal, and difficult to quantify; however, it is not about what the stroke survivor does in the gym, it is about what they get from the gym, in terms of mastery and vicarious experience, which builds their self-efficacy. All participants have a patient held record, on which they record what exercise they do each week, along with their blood pressure and weight. This not only puts the participants in control, but also enables them to see their progress; as Charlotte explained (lines 37-41);

“by having a piece of paper which actually they write down their weekly achievements, even though the patients will still say to us they feel as though they’re only at 80% or 90% of their pre-stroke state, they still feel as though they’d failed but having it written down to see that in the space of a couple of weeks they’ve doubled their endurance and their tolerance is that written affirmation that they are improving.”

Careful, though unobtrusive supervision is required, as some participants tend to compare themselves to peers, in a competitive way, during the exercise sessions, and may push themselves too hard.

Staff roles, skills and approach

There are a number of core skills and attributes, that are needed to run the ASPIRE programme, as Charlotte explained; (lines 51 – 52 and 104 – 112);

“From a staff point of view I feel that the most important element that the staff need to have is to be approachable and to be informal but professional at all times....I think the biggest thing is to have observation skills. I think that most staff have got the academic knowledge base and the professional skills and experience but the best thing to do is to actually watch and as with most patients on the ward it’s never the one that’s shouting and ringing their bell that needs you, it’s the one that’s very quiet in the corner. I think that with that, that if a patient doesn’t turn up for a week, to make sure you phone them up and follow it up to make sure that they’re not struggling at home. And I think to not be too professional and hide behind your uniform. What patients want is they want you to be genuinely interested in how they are and actually listen to the answer which I think as individuals we’re really bad at doing but it’s those subtle cues that are actually what people want you to concentrate on.”

Volunteer Sue, also stresses the importance, of having approachable, knowledgeable professionals at ASPIRE (lines 53-8);

“You feel there are people like consultants and nurses who you can ask questions; professional people who you can ask anything each week if anything’s worrying you. Obviously if there are very important things during the week you go to your doctor, but most of the time it is very small things and it is nice to be able to ask. Things like not sleeping at night, tablets and aches and joint muscles are often said. The best thing is that they are reassured to know that you are there to iron out any little worries. Often you can’t talk with your husband or your partner as they are still coming to terms with what has happened”

Diana, a relatively new rehabilitation assistant, recognised the importance of having less stroke specialist though still approachable people, like herself, involved (lines 57 - 62);

“And sometimes feel reassured that if I don’t know the answer then I can say ‘ooh I’ll just, let me just check. And I think sometimes it’s a bit reassuring that they say oh someone else is finding out, there’s another person finding out. There’s another person finding out for them and the questions are being spread. There’s more people, they’ve asked more people maybe it’s a bit reassuring for them as well”

In terms of staffing, there is flexibility and overlap between roles, in the way the programme is delivered, as Kate, a rehabilitation assistant explained (lines 32 – 41);

“You’re not just having a massive group that you can’t get around to everybody and get to hear about everybody’s problems. We definitely are able to do that. And I think we have very skilled..... sort of medication wise we have somebody who can deal a lot with that, we have obviously yourself who can deal a lot with the physical aspect and then myself who just does bits of the gym and blood pressure and just the sort of guidance and advice and comfort for patients. I think we’re very versatile in the roles we can play and we offer a wide range and I think that all aids to what they get from the ASPIRE group. So for people who take that up...another group on or want to create another group they need to just think about those things, keeping it small, keeping it one to one, having diverse characters and people who have diverse roles that can deal with different situations.”

The contribution, of each of the individual professional roles, should not be underestimated, as Charlotte (a nurse) explained (lines 68 – 87);

“I think that it is perceived that the skills that I bring are from a medical aspect so very much from a medication point of view and looking at side effects and the fact that I can prescribe proves particularly useful and

there's no time delay of the patient then being given a recommendation, having to make an appointment with the GP but I think a lot of the time people just want reassurance with their medications and the side effects that, or the physical problems they're experiencing are normal or abnormal, whether to worry about them because as health care professionals when people are in hospital we do make them paranoid about medication and blood pressure by the nature of our obsessiveness with it really. So I think a lot of the time they just want to talk about it and know the little twinge they have is normal so I don't think you necessarily need to be able to prescribe to provide that support but there's a perception that that makes it useful. The other thing I think from a benefit, I think having a nurse there is very useful because the physio part of the role is very structured and I think in that hour of the exercise the physiotherapist is looking very much at the exercise and that's essential and I think my role is perhaps much more fluid in that time which gives me the opportunity to do a much more counselling role and whether that's for the stroke survivor, whether that's for the carer, whether that is a marriage guidance counsellor it doesn't really matter and it probably changes on a weekly if not a half hourly basis but I think because people see me as not being torn in having to be overly involved from an exercise point of view here's the perception I'm more approachable from that element and I find that I do spend a lot of time chasing up blood results and test results that perhaps the medical consultant has requested so it's having a bit of closure on a lot of the medical issues."

Volunteers, all stroke survivor peers, are now a critical part of the group, as Dave said (line 356-7);

"to help out and basically I think the volunteers should be ex-stroke victims or survivors".

Dave explained what he thinks he brings to the group (lines 346-7);

"I hope I give people the incentive to do a bit more than they thought they could and go home with a target and a goal."

Sue's approach is different, though equally valuable (lines 68-70);

"Well, I hope I bring encouragement most of all, and to help build their confidence again, by all the time encouraging them. You have to build confidence little by little and sometimes things can happen that can damage it for a bit."

Picking the right volunteers is crucial. Dave suggested that (lines 382-3 & 389 – 90);

"Some people shouldn't be volunteers and some people should. You would be able to tell at interview. Well I think they should be assessed ... to see whether you think people are okay to do it."

Furthermore he feels they should be (line 376); *“Positive thinking, outgoing and pleasant and nice.”* To enable volunteers to be able to support the group, they need training, as Dave suggested (lines 330-6);

“Training topics like safety on the machines, how they work and being able to talk to people. I try to speak to people so they don’t realise how the times going on! You can speak to them and they would be like ‘yeah, yeah, yeah’ and the next thing you know they have done 5 minutes. Things like encouragement helps for that, but it’s knowing what you can do and what you can’t do really. It is difficult to say. Basically most important thing is safety on the machines or trying to egg them on for an extra minute or an extra bit of speed, but within the safety boundaries.”

Overall, the most important quality for volunteer, are that they embrace the ethos of the ASPIRE programme, which supports participants, to gain the confidence they need, to take control of their own recovery and rehabilitation. Other than that, the diversity amongst volunteers, is crucial, to match the diversity of the participants. This diversity is in terms of their own stroke experience; severity, length of inpatient stay and residual impairments. More importantly, this diversity is in terms of post-stroke experiences and personal qualities; Dave is the most goal focused; Sue is a good listener and brings a female perspective; other volunteers bring a sense of humour, compassion, experience of return to work and share the experience of their partners as caregivers.

Caregivers at ASPIRE

Caregivers are also welcome, to accompany the stroke survivors, to the session, though this is entirely optional. They may use the time as respite; to go shopping or for a cup of coffee; or take the opportunity to sort out financial or their own health issues. For some caregivers, attendance at the ASPIRE group provides some relief from the burden of caregiving, by providing a break, from the frustrating situation of dealing with emotional and behavioural issues (Pierce et al, 2007).

Caregivers may choose to be actively involved in the session; helping, supervising or prompting the stroke survivor to use equipment or record their exercise; or they may sit and watch, or chat with other participants or staff. Even though the gym

gets rather crowded at times, the presence of an extra person who knows an individual stroke survivor well is invaluable in running the session, as they can help encourage and monitor their stroke survivor. Some caregivers need guidance from the ASPIRE team, to provide the appropriate level of support. Caregivers also benefit from participating in the information sessions; as Brenda explained (lines 192 -194);

“And also it was just full of information so I’m always one to learn something, you know you’re never too old to learn anything, so that was really good to go and have the information session.”

Charlotte (stroke nurse consultant) explained her view of what benefits caregivers get from attending ASPIRE (lines 22- 32);

“I think probably you could almost say they get as much if not more out of the sessions. I think it’s the reassurance that what they’re going through isn’t unique to them. I think it’s their ability to let their guard down and to be themselves and be honest about their emotions and I get the impression that they can’t do that even with their family. They feel as though they’re disloyal to their partner if they do that. I feel it’s their.... it’s as much their time as it is for the person that’s had the stroke and whilst we offer them the opportunity to use this as their time out so that they can go off shopping if they want to, the fact that the majority of them choose to stay, and the fact that the majority of them choose to still come even when they’re no longer needed to be the driver and the sort of transport person goes to show the benefit that they get out of it. And again they’re the ones that will often keep in contact with us afterwards and feel as though they become part of a little family and team really.”

Although not every stroke survivor attends with a carer, the caregivers that do attend, whether partners, children or parents, are seen as an equally important part of the ASPIRE programme, as the stroke survivors, with as much to gain and also as much to contribute, from attending. This is supported by Lou et al (2016) who suggest that carers may be a valuable asset in the rehabilitation process.

Information sessions

It is important to get the right atmosphere in the interactive information sessions, to give people the confidence to share experiences, not just find out facts. Participants and volunteers are encouraged to ask questions and express their views, plus there’s often a lot of laughter. As Kate explained (lines 11- 14);

“we then have extra talks afterwards which they also gain more information about things that they never really think about at that time and we offer them that sort of advice and guidance and I think they take a great deal away from that as well and they feel free to open up and talk about things that they might not otherwise have spoken about if we didn’t offer them the ASPIRE group.

In contrast, Lily (a dietician) despite being involved in delivering the ASPIRE programme for 3 years, clearly preferred the more didactic approach she used in cardiac rehabilitation groups (lines 40 – 46 and 74 – 79);

“I think certainly from my experience of doing the cardiac rehab I think having a visual aid for them because I do a presentation slide show and I actually explain with pictures, with wording, with product pictures what I’m trying to explain and they can follow that whilst listening whereas something I think with ASPIRE here the way we run it is that sometimes we can go off track you know when they start to ask different things whereas if it’s more structured, that’s just my experience what I find with the cardiac rehab, if you actually have a visual aid to give the presentation and training you find it more beneficial..... I find it much easier to give the presentation that’s there, if someone wants to read anything I say or forgot what I just said the line before they can read it, rather than... I don’t know.... I just find sometimes it’s better to have a visual aid whilst giving training as well.....but on the other hand you don’t want to formalise it too much, you want to make sure you keep it interactive and they feel it’s an environment where they can ask questions and be interactive, but it’s finding the balance between the two.”

Three key issues were identified in the interviews with staff and volunteers. The first was the initial experiences of attending ASPIRE, from the perspective of stroke survivors; as volunteer Dave explained (lines 66-70);

“Because when I first came I was terrified, I have to be totally honest going there for the first time you don’t know what to expect. Even though I now go on the wards and tell people what to expect, I didn’t know what to expect and I don’t think they (new ASPIRE referrals) know what to expect, or how it will benefit them”.

Sue, a volunteer at ASPIRE for more than 3 years agreed (lines 136 – 141);

“I think they feel a bit daunted, and not feeling that they want to be in a group as there is always that feeling isn’t there? Worrying about being put on the spot but ASPIRE is very good for not doing that. I always say to people ‘don’t worry about being put on the spot, all you have to do is listen, and if you do want to pipe up with something do’. There is not any pressure in ASPIRE which makes people feel relaxed and confident that ASPIRE is a good programme, which it is”.

The second was the different approaches to the information sessions as highlighted by Lily. The third was the need to be more structured in terms of the training provided for volunteers.

PDSA 4: Act

Changes to address these three key issues are discussed in the planning phase for PDSA cycle 5.

4.6 PDSA cycle 5; 2010 – 2012 (includes phase 2)

PDSA 5: Plan

A number of changes were planned to support new starters in PDSA 5. The volunteers came up with the idea of visiting stroke survivors, just prior to discharge from the acute stroke unit, to let them know about ASPIRE, and also to be a familiar face for their first attendance. The author ensured that after the initial individual assessment, as a new participant was being inducted to the gym equipment, they would be deliberately taken to a piece of equipment next to an experienced participant and introduced, then left to chat for a few minutes. In addition, either a peer volunteer or a member of the staff team would support the new participant throughout their first session.

In order to ensure all staff members, who facilitated information sessions understood the ethos of ASPIRE, a face to face briefing about the person-centred ethos was given then joint facilitation and monitoring of the information sessions with new staff members. To support volunteers and ensure they were appropriately trained, in addition to the trust induction and mandatory training, which covered issues such as confidentiality, equality and diversity and infection control; regular meetings were held with the volunteers to check if they had any concerns or questions. Old and new volunteers were given a thorough reminder of the use of the gym equipment, so they could remind participants, and any new volunteers were closely supervised, then partnered up with an experienced volunteer for their first few sessions.

PDSA 5: Do

A summary of the revised programme is given in table 32.

Table 32: ASPIRE programme 2012

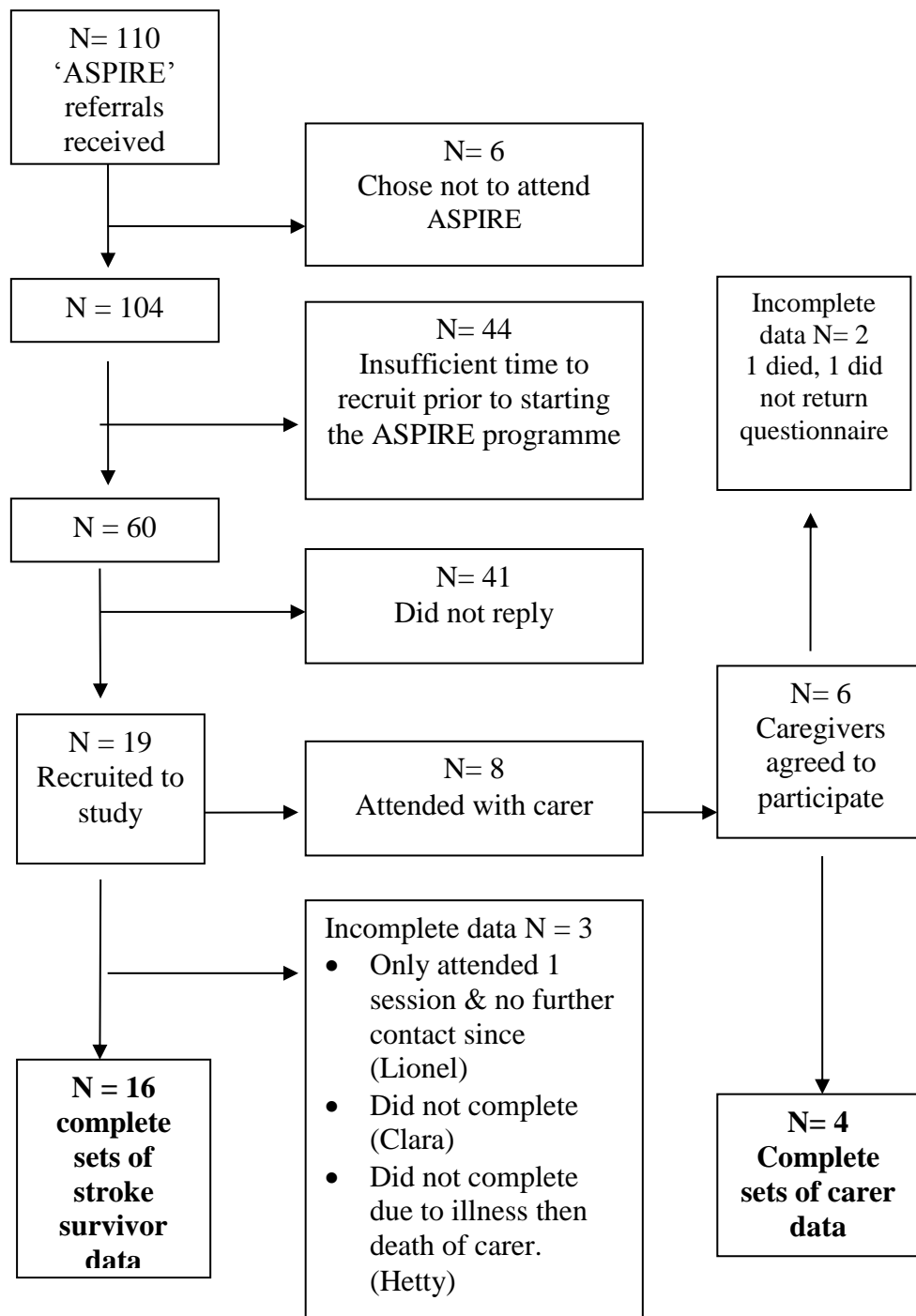
| Name of programme | ASPIRE |
|--------------------------|--|
| Assessment | Individual assessment & information session plus discussion about aims of attending programme in relation to recovery from stroke and also secondary prevention. Blood pressure, weight, BMI, waist circumference. |
| Participants | Up to about 30 adult stroke survivors and their caregivers of all ages. Most have mild to moderate residual impairments mostly of communication, cognition, sensation or upper limb movement. A small proportion use a wheelchair for mobility and may be hoisted or use a transfer aid and assistance to transfer or need assistance plus a gait aid to stand and are able to take a few steps at most. |
| Exercise session | Up to 60 minutes of individually tailored exercise including cardiovascular, balance and strengthening exercise in the large outpatient rehabilitation gym. Greater variety and numbers of exercise equipment. Each participant builds up gradually on all the activities in their individual circuit – initially having frequent rest breaks. |
| Information session | 30 minutes interactive discussion held in seminar room – with participants from both exercise sessions. Tea and coffee served by volunteer – dysphasic ex-ASPIRE participant. Information sessions as before though with volunteers both contributing to and leading sessions. |
| Supporting documentation | Patient held ASPIRE record details medication, risk factors, weight & blood pressure, stroke recovery and secondary prevention goals plus exercise programme. |
| Overall staffing | Consultant therapist – rehabilitation, Rehabilitation assistant, Consultant nurse – Stroke plus several regular volunteers |
| Timing | Thursdays with assessments between 9.30 am and 10.30am or between 11.30am and 12 noon. Two separate exercise sessions held 10.30 -11.30, the other from 12 noon till 1pm. Participants have the choice as to which session to attend and can swap attendance time from week to week. Information session with all participants from both exercise sessions held from 11.30am – 12 noon |

PDSA 5: Study including findings phase 2 research

For this fifth PDSA study phase, in addition to information from the author's 'praclog', 'doclog' and views of colleagues and volunteers involved in running the programme, the author used findings from phase 2 of the research study to inform the changes needed. Phase 2; for methods see chapter 3, sections 3.13 –

3.17; was looking at outcome measures identified from analysis of the themes in phase 1 (table 15). Recruitment to phase 2 of the study was significantly more challenging than to phase 1, partly due to the tight timescales, and partly due to a much lower proportion of those being approached consenting to participate. As a consequence, the recruitment in phase 2 spanned a period of more than one year. Details of recruitment and retention to phase 2 are summarised in figure 2.

Figure 2: Recruitment & retention to Phase 2



Of the 110 referrals received for the ASPIRE programme during this phase, only 104 people decided to attend; this is in line with the usual referral to participation rate. As the time from discharge to starting ASPIRE is always kept as short as possible, there was only sufficient time to send out letters inviting participation to the study, receive replies and send out research questionnaires, to 60 out of these 104 potential participants between receiving the referral and their ASPIRE start date, thereby missing out on a potential further 44 recruits to phase 2. Of these 60, 41 did not reply, the other 19 replied and then agreed to participate in the study. This response rate of 31.7% is high for questionnaires sent by post, which generally have low response rates (Hicks, 1999). Many of those who did not reply later said they would have been willing to participate, if they had realised how much they would benefit from attending the ASPIRE programme. At the time of receiving the research patient information leaflet and questionnaires, they were uncertain of whether they would be attending ASPIRE regularly and were generally feeling a bit overwhelmed. In hindsight, a personal approach by a member of the stroke research nurse team may have increased recruitment.

The 19 who agreed to participate were typical of ASPIRE participants in terms of age, gender and level of residual impairment. Of the 19, eight attended with caregivers, six of whom also agreed to participate. Of the 19 stroke survivors and six caregivers who agreed to participate in the study, not all completed the ASPIRE programme, and not all returned their final sets of questionnaires. The rate of non-completion of ASPIRE was in line with that typically experienced; one, Clara, wanted to take a break over the worst of the winter weather then did not return; one, Hetty, was due to the illness and subsequent death of her partner; and one person Lionel only attended once. Another participant, Simon, did not complete ASPIRE as he started a new, less stressful job after only two sessions; he returned his final set of questionnaires, so is included in the analysis.

Altogether 16 complete sets of data from stroke survivors were received. Only four complete sets of carer information from six caregivers were received; one did not return the questionnaires and one caregiver died.

4.7 Phase 2 participants

The characteristics of all 19 stroke survivors (referred to by pseudonyms), who participated in phase 2, are presented in table 33. These characteristics include; age, gender, risk factors, past medical history and effects of stroke, at the time of first attendance at the ASPIRE programme. As can be seen, participants were aged between 38 and 79 years and the majority of participants were male (11/19), with a variety of impairments, though none with more than mild cognitive or communication difficulties. Table 33 also includes details about ASPIRE attendance, and whether questionnaires were returned or not. The six informal caregivers (three men, three women), were all spouses or partners and of a similar age to the stroke survivor they accompanied; no other details about the caregivers were collected.

These participants broadly reflect the typical ASPIRE population, which tends to have a slightly greater proportion of younger, predominately male and more able stroke survivors than the local stroke population as a whole, though there were no participants aged over 80 which is unusual for ASPIRE. The predominantly female, older and less able stroke survivors leaving the acute stroke unit tend to have an inpatient rehabilitation unit stay after the acute phase (Appelros et al, 2010). These patients are dependent on staff from a different healthcare provider making the referral, and although many of those staff have visited the ASPIRE programme they only refer a small proportion of their patients. At the time this could be due to a number of reasons including; lack of awareness of the potential benefits of the programme to this more dependent group; an assumption by the potential referrer about the level of dependency appropriate for the ASPIRE group; or difficulties with transport. More recently this healthcare provider has set up a sister group to ASPIRE, called 'Life after Stroke'

Table 33: Characteristics of stroke survivors participating in phase 2

| Pseudonym Gender (M/F) & Age at stroke (years) | Civil & employ- ment status at date of stroke. | Risk factors & relevant past medical history | Type of stroke. Residual effects of stroke at time of attendance at ASPIRE including physical abilities, cognition, communication & mood. Attendance at ASPIRE |
|---|---|---|---|
| Cyril M 79 | Married. Retired. Attended with wife. | Hypertension Emphysema Osteoarthritic knees | Left lentiform nuclei infarct, small vessel disease. Mobile with quad stick & close supervision / minimal assistance. Reduced balance. Weakness and increased tone in upper limb. Short term memory difficulties otherwise no cognitive or communication issues. Completed 12 sessions plus review |
| William M 79 | Widowed Retired Attended alone | Hypertension Type 2 Diabetes Hypercholester olemia COPD. Chronic renal failure | Right frontal lobe infarct Mobile with quad stick & supervision. Reduced balance. Weakness and loss of dexterity in upper limb. Short term memory difficulties. No communication difficulties Completed 12 sessions plus review |
| Alan M 77 | Married. Retired. Attended with wife. | Carotid artery stenosis. Diet controlled diabetes. Hypercholester olemia. Gout. | Left Middle Cerebral Artery Infarct. Independently mobile no aids. No upper limb difficulties. No cognitive or communication issues. Completed 12 sessions plus review |
| Richard M 76 | Lives alone Retired. Attended alone. | Atrial fibrillation Previous right total hip replacement | Clinical CVE plus subdural haematoma following fall – drained by burr-hole. Independently mobile no aids. Shoulder pain and weakness in upper limb. Completed 12 sessions plus review |
| Jack M 69 | Married. Retired. Attended with wife | Hypertension Atrial fibrillation Stress Obesity Lack of physical activity Previous back problems | Clinical CVE Independently mobile no aids. No upper limb difficulties. Dysarthria No cognitive issues. Completed 12 sessions plus review Wife did not return final questionnaire despite reminder. |
| Lionel M66 | Married Retired Attended alone | Previous myocardial infarction plus stent Type 2 Diabetes – diet controlled Stress | Right frontal infarct. Weakness and sensory changes left arm and leg. Full functional recovery upper limb. Independently mobile no aids Attended once only. No further contact and did not return second set of questionnaires. |

| Pseudonym Gender (M/F) & Age at stroke (years) | Civil & employ- ment status at date of stroke. | Risk factors & relevant past medical history | Type of stroke. Residual effects of stroke at time of attendance at ASPIRE including physical abilities, cognition, communication & mood. Attendance at ASPIRE |
|---|---|--|---|
| Jeff M 65 | Married. Retired. Attended with wife. | Atrial fibrillation Hypertension | Right internal capsule infarct Independently mobile no aids though slightly hemiplegic gait pattern. Stiff oedematous hand. Dysarthria. No cognitive problems Completed 12 sessions plus review |
| Derek M 60 | Lives alone Working full time Attended alone | Patent foramen ovale Hypertension Hypercholester olemia Ex-smoker Stress Excess alcohol | Multiple posterior infarcts Independently mobile no aids. No upper limb difficulties. Difficulties with memory and following complex instructions Fatigue. Low mood & anxious Completed 12 sessions |
| Simon M 53 | Married Working full time Attended alone | Hypertension Hypercholester olemia Stress | Acute intracerebral haemorrhage in right lentiform nucleus Independently mobile no aids. No upper limb difficulties. No cognitive or communication issues Fatigue Attended 2 sessions only due to new job. Completed questionnaires. |
| Dick M 51 | Married Working full time Attended alone | Athero- sclerosis Carotid artery stenosis. | Right middle cerebral artery infarct Independently mobile no aids. No upper limb difficulties. Dysarthria No cognitive issues Completed 12 sessions plus review |
| Dan M 38 | Married. Working full time Attended alone | Hypertension Diet controlled diabetes. | Clinical CVE Independently mobile no aids. No upper limb difficulties. No cognitive or communication issues. Completed 12 sessions plus review |
| Clara F 77 | Widowed Retired Attended alone | Hypertension Diet controlled diabetes. Hypercholester olemia | Clinical CVE Mobile with stick. Reduced balance. Numerous falls No upper limb or communication difficulties. Difficulties with short term memory Completed 7 sessions then did not complete or return second set of questionnaires |
| Jenny F 76 | Married. Retired. Attended alone | Atrial fibrillation | Multiple temporo-parietal infarcts Independently mobile no aids. No upper limb difficulties. No cognitive or communication issues. Completed 12 sessions plus review |

| Pseudonym Gender (M/F) & Age at stroke (years) | Civil & employ- ment status at date of stroke. | Risk factors & relevant past medical history | Type of stroke. Residual effects of stroke at time of attendance at ASPIRE including physical abilities, cognition, communication & mood. Attendance at ASPIRE |
|---|---|--|--|
| Marjorie F 74 | Married. Retired. Attended with husband | Hypertension Previous CABG Prosthetic aortic valve | Clinical stroke Independently mobile no aids. Altered sensation and dexterity in hand. Expressive dysphasia. Reduced concentration Completed 12 sessions plus review |
| Vanessa F 74 | Married. Retired. Attended with husband | Type 2 Diabetes Hypercholester olemia Ex-smoker Lack of physical activity Overweight | Left middle cerebral artery infarct Independently mobile no aids. Minor weakness right hand. Mild dysphasia Dyscalculia, sequencing & memory difficulties. Completed 12 sessions plus review |
| Kate F 72 | Married. Retired. Attended alone | Previous stroke Hypercholester olemia | Lacunar infarcts Independently mobile with stick. Sensory issues with hand. Reduced balance. No communication issues. Some short term memory difficulties Very anxious Completed 12 sessions plus review |
| Penny F 70 | Married. Retired. Attended with husband | Previous myocardial infarction Atrial fibrillation Hypertension | Right basal ganglia infarct Independently mobile no aids. No upper limb difficulties. No cognitive or communication issues Fatigue Completed 12 sessions plus review |
| Hetty F 62 | Living with partner Retired Attended with partner | Hypertension | Left middle cerebral artery infarct Right upper limb weakness with reduced function and dexterity Independently mobile with stick though with slight footdrop Expressive & receptive dysphasia Short term memory difficulties Completed 10 sessions before her partner became ill and then died. Second set of questionnaires not returned and under the circumstances no reminder was sent. |
| Sarah F 58 | Widowed. Working part time Attended at times with teenage children | Hypertension Diabetes Lack of physical activity Stress Obesity | Right middle cerebral artery & lacunar infarcts Independently mobile no aids. No upper limb difficulties. Distance perception difficulties Dysarthria Anxious Completed 12 sessions plus review |

4.8 Phase 2 Results and analysis

In the following section, the Pre- and Post- ASPIRE scores for each of the four standardised assessment tools (Stroke Self-Efficacy Questionnaire, Cerebrovascular Attitudes and Beliefs scale, Stroke Knowledge Test, and Hospital Anxiety and Depression Scale), for the 16 full sets of data for stroke survivors are presented in both tabular and graphical format, and the findings analysed. With only four full sets of data for the caregiver strain index, only descriptive statistics are presented, as there is insufficient data to do more detailed analysis. It should be noted that with small numbers of participants, a Pre-Post study design, and no comparison group, the focus is the responsiveness and usability of the tools rather than the impact of the ASPIRE programme as assessed by these standardised tools.

As the numbers involved in phase 2 of the research study were small, additional reflections on the usefulness of the Stroke Self-Efficacy Questionnaire, the CABS-R and the HADs have been gathered from the author's 'praclog', as these questionnaires were used routinely, with other ASPIRE participants, not involved in phase 2 of the research project. These additional insights are included in the discussion on strengths and limitations of phase 2 in 4.11.

Stroke Self-Efficacy Questionnaire

Stroke self-efficacy scores, for participants in phase 2 of the research study, both before and, where available, after attending the ASPIRE programme, are detailed in table 34. As can be seen, a significant proportion of participants are close to the maximum score (130) before starting ASPIRE, thus limiting the amount of change possible i.e. for this cohort of participants this assessment tool exhibited a ceiling effect. Although the scores for the majority of the participants improved (11 out of the 16 full sets of data), it was mostly by a small amount (less than 10 points); however, Cyril, Jeff, Marjorie and Sarah, all of whom started with relatively low scores, all improved markedly. Scores for four of the participants (Alan, Jack, Vanessa and William) deteriorated by a small amount; however, Derek's score was much lower after attending the ASPIRE programme, than before. The scores for participants, for whom both sets of data are available, are illustrated in figure 3.

Overall, it can be seen that there was marked individual variation, in the impact of attending the ASPIRE programme, on Stroke Self-Efficacy questionnaire scores.

Figure 3: Pre and post ASPIRE stroke self-efficacy questionnaire scores

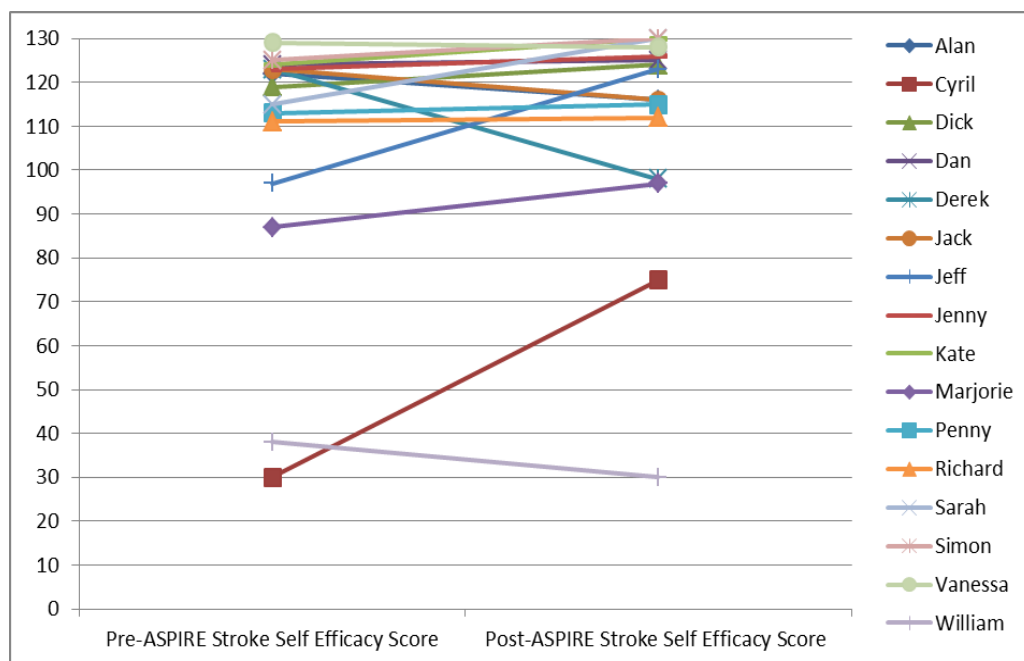


Figure 3: Pre-ASPIRE and Post-ASPIRE stroke self-efficacy scores for individual participants.

Table 34: Stroke Self-Efficacy questionnaire scores

| Pseudonym | Pre ASPIRE Stroke Self-Efficacy questionnaire scores | Post ASPIRE Stroke Self-Efficacy questionnaire scores |
|-----------|--|---|
| Alan | 122 | 116 |
| Clara | 58 | No data |
| Cyril | 30 | 75 |
| Dick | 119 | 124 |
| Dan | 124 | 125 |
| Derek | 123 | 98 |
| Hetty | 66 | No data |
| Kate | 123 | 130 |
| Jack | 123 | 115 |
| Jeff | 97 | 123 |
| Jenny | 123 | 126 |
| Lionel | 128 | No data |
| Marjorie | 87 | 97 |
| Penny | 113 | 115 |
| Richard | 111 | 112 |
| Sarah | 115 | 130 |
| Simon | 125 | 130 |
| Vanessa | 129 | 128 |
| William | 38 | 30 |

Stroke self-efficacy scale statistics

As detailed in table 34, and illustrated in figure 3, most participants were close to, or at the maximum score, though there was some variability between individuals, for this questionnaire, before attending ASPIRE. Hence, although the data could be treated as interval / ratio, as they are not normally distributed, only the median and the inter-quartile range are shown in table 35 and a non-parametric test was used. Using a Wilcoxon test on the data (T=40.5, N=16) the results were found to be non- significant at $p > 0.05$ for a one-tailed test.

Table 35: Stroke self-efficacy scale statistics

| Statistic | Median | Inter-quartile range |
|---------------------------|---------------|-----------------------------|
| Pre-ASPIRE scores | 120.5 | 19 |
| Post-ASPIRE scores | 119.5 | 22 |

Analysis of findings - Stroke self-efficacy questionnaire

Although the majority (68.75%) of the completing group improved and of these, a small number, (25%) of participants started with low scores and made significant gains (see figure 3), the overall results were non-significant. This may have been due to the ceiling effect, demonstrated by this tool with this cohort, reflecting a number of participants with little or no impairment, thereby limiting the potential for capturing positive change. It is not known why scores decreased in a small number (31%). It is known that fatigue is negatively correlated with self-efficacy (Muina-Lopez & Guidon, 2013); it is not known whether fatigue affected self-efficacy scores in this study, as the level and type of fatigue (mental or physical), was not formally assessed, for any of the participants. Of the three participants; Penny, Simon and Derek, who had self-reported fatigue noted as an issue in their clinical record, only Derek's self-efficacy score decreased markedly over time, the other two's scores improved slightly.

Cerebrovascular Attitudes and Beliefs Scale – exercise subscale

The total Cerebrovascular Attitudes and Beliefs exercise subscale (CABS-R) scores for participants, before and after attending the ASPIRE programme, are detailed in table 36, and illustrated in figure 4. The overall scores relate to beliefs about the benefits and barriers to undertaking exercise, plus beliefs about the susceptibility to, and severity of stroke. As clearly illustrated in figure 4, before

starting ASPIRE, a significant proportion of participants were close to the maximum score (100), where a higher score relates to higher exercise self-efficacy thus limiting the amount of change possible i.e. for this cohort of participants, this assessment tool exhibited a ceiling effect. Only two participants reached the maximum possible score after ASPIRE, and the three participants for whom there was no post-ASPIRE data, all started with fairly low scores.

Cerebrovascular Attitudes and Beliefs Scale – exercise subscale statistics

As detailed in table 36 and illustrated in figure 4 most of the participants were at or close to the maximum possible score for this tool even before attending the ASPIRE programme thus exhibiting a ceiling effect and limiting the amount of positive change possible. As table 37 and figure 5 indicate, there was a one point increase in the median score for the group after attendance at the ASPIRE programme, and increased variability in scores as shown by the increase in inter-quartile range.

Table 36: Cerebrovascular Attitudes and Beliefs Scale – exercise subscale – scores

| Pseudonym | Pre ASPIRE Cerebrovascular Attitudes and Beliefs Scale – exercise subscale – scores | Post ASPIRE Cerebrovascular Attitudes and Beliefs Scale – exercise subscale – scores |
|------------------|--|---|
| Alan | 83 | 76 |
| Clara | 76 | No data |
| Cyril | 71 | 80 |
| Dick | 92 | 100 |
| Dan | 79 | 74 |
| Derek | 78 | 85 |
| Hetty | 68 | No data |
| Kate | 91 | 79 |
| Jack | 76 | 75 |
| Jeff | 88 | 88 |
| Jenny | 85 | 91 |
| Lionel | 69 | No data |
| Marjorie | 76 | 96 |
| Penny | 76 | 77 |
| Richard | 72 | 78 |
| Sarah | 76 | 91 |
| Simon | 96 | 100 |
| Vanessa | 81 | 81 |
| William | 84 | 58 |

Figure 4: Cerebrovascular Attitudes and Beliefs Scale – exercise subscale – scores

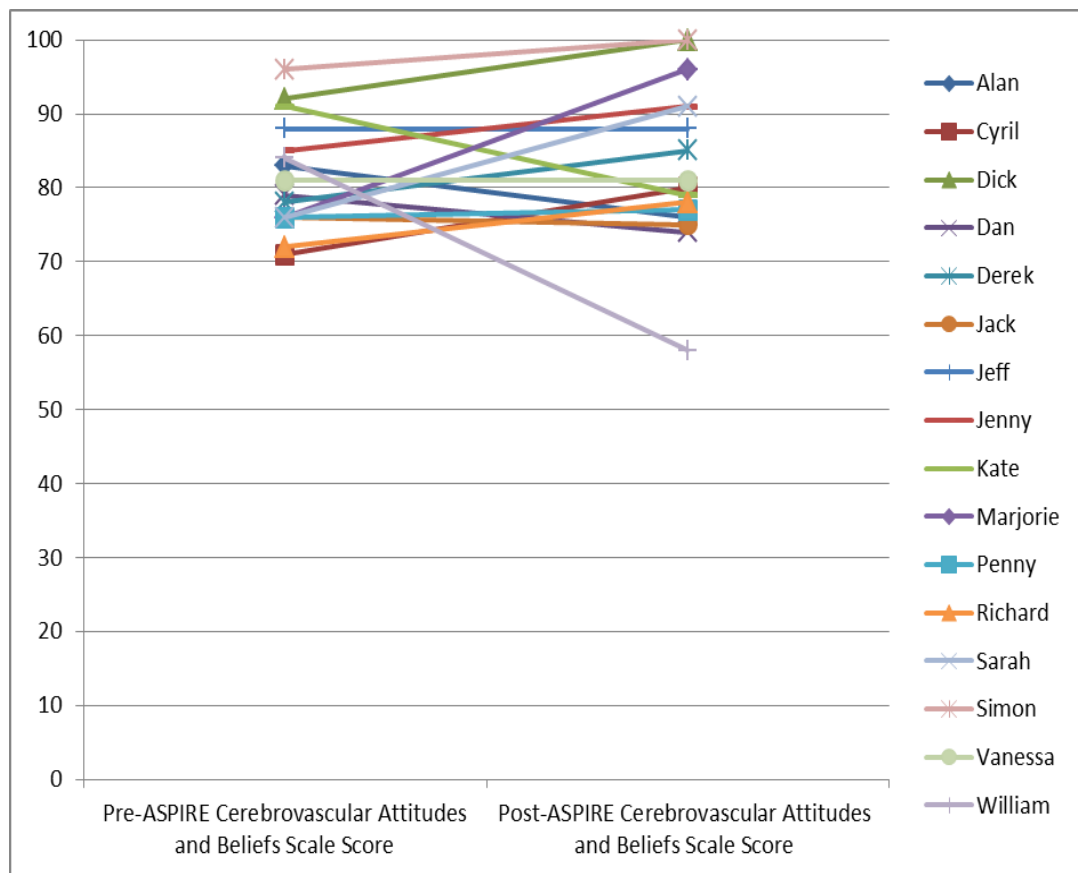


Figure 4: Pre-ASPIRE and Post-ASPIRE CABS-R scores for individual participants.

As ordinal data, the median CABS-R scores, and inter-quartile range, pre- and post-ASPIRE, are shown in table 37 and illustrated in figure 5. Using a Wilcoxon test on the data ($T = 34.5$, $N = 14$) the results were found to be non-significant for a one-tailed test.

Table 37: Cerebrovascular Attitudes and Beliefs Scale – exercise subscale – statistics

| Statistic | Median | Inter-quartile range |
|--------------------|--------|----------------------|
| Pre-ASPIRE scores | 79 | 9 |
| Post-ASPIRE scores | 80 | 15 |

Figure 5: Cerebrovascular Attitudes and Beliefs Scale – exercise subscale – statistics

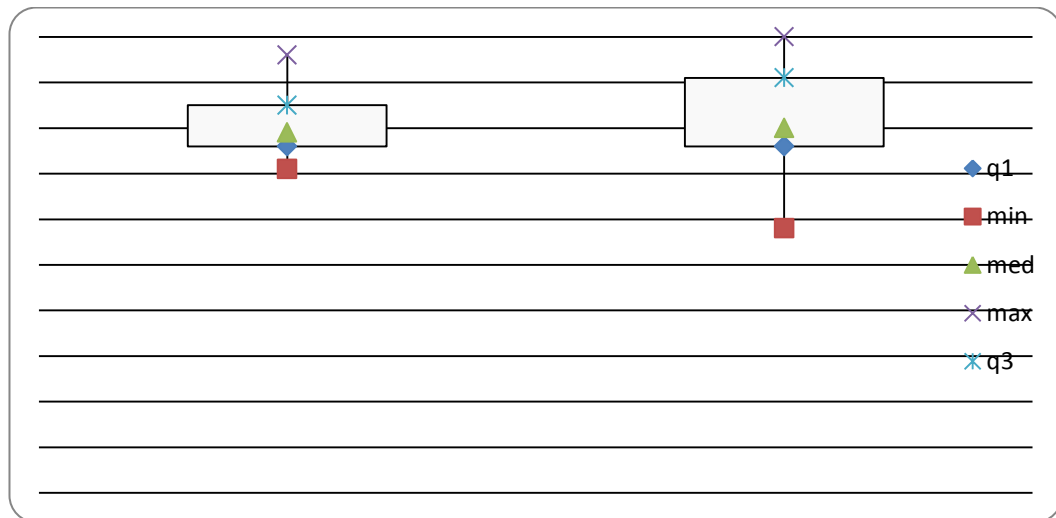


Figure 5: Pre-and Post-ASPIRE median CABS-R scores (med) plus lower quartile (q1), upper quartile (q3), and inter-quartile range.

Analysis of findings - Cerebrovascular Attitudes and Beliefs Scale – exercise subscale

The high scores, and therefore positive attitude towards exercise, demonstrated by the participants, is not unexpected, as they had agreed to participate in the ASPIRE programme, whilst knowing both at the referral and appointment making stages, that the programme includes an exercise component. It could be argued that the ASPIRE population is self-selecting as favourably disposed towards exercise.

The lack of a statistically significant trend in CABS-R scores, after the ASPIRE programme, compared with before, appears to be in contrast with the findings of the phase 1 interviews. A contributory factor might have been the marked variation between participants. Figure 4 shows that scores improved for nine participants, deteriorated for five participants (Alan, Dan, Kate, Jack and William), plus stayed the same for the remaining two participants. Two of those whose scores had deteriorated (Kate and Alan), had commented on their questionnaires that comorbidities were causing pain on exercising (Kate due to osteoarthritis of the knees and Alan due to gout and / or ischaemic leg pain). In both cases this affected

those items on the scale, relating to benefits and barriers to exercising, and thus impacted on the overall score.

On reflection, it should be noted that phase 1 participants were only interviewed once, after completing ASPIRE so interviews indicate a positive view towards exercise, rather than a change in attitude due to the impact of the ASPIRE programme. The limited change in attitudes to exercise found by the CABS-R in phase 2, may also be due to some individuals who had been positive about exercise prior to their stroke, but who had found the experience of exercising after their stroke, more challenging than they had expected. Without asking those individuals it is difficult to be certain. Jones (2005) also found that inexperienced exercisers, especially those with high levels of self-efficacy (as was the case with many of those in phase 2), tended to have overly ambitious expectations from an exercise programme, were therefore less likely to complete the exercise programme, and more likely to be disappointed with the results.

It may also be that the Cerebrovascular Attitudes and Beliefs Scale is inappropriate for use in a post-stroke population and unable to detect change in this group; as previous studies (Sullivan et al, 2009; Sullivan et al, 2010) have all been carried out, in those not having had a stroke. As noted in the author's 'doclog', an indication of this came from Vanessa, who at her final session, whilst on the cross trainer, with a big smile on her face, said that '*my friends would not believe it if they could see me now, I always hated exercise and loathed gyms before*'. This type of view is common in the author's experience, in that ASPIRE participants generally become more, rather than less, positive about exercise, as they gain confidence and abilities. Vanessa's score; however, remained unchanged at 81. It may be that the Cerebrovascular Attitudes and Beliefs Scale is more predictive of future exercise intentions; it would therefore be interesting to see if Vanessa has continued to exercise regularly. Continuation of exercise for the long term, as identified by the phase 1 interviews, is of much more importance than a short term change in attitude, not only for the reduction in blood pressure (Whelton et al, 2002), but also the likely reduction in vascular events (Hackam & Spence, 2007), and hypothesised positive impact on cognitive function (Tyndall et al, 2013).

Stroke Knowledge Test

The Stroke Knowledge Test scores for participants, before and after attending the ASPIRE programme, are detailed in table 38 and illustrated in figure 6; with most individuals, and the group as a whole, showing marked gains in stroke knowledge. Overall Stroke Knowledge Test scores, even before attending ASPIRE, were slightly higher than expected, with five out of the 19 participants (26%) getting at least three-quarters of the answers correct, and 17 of the 19 participants i.e. a total of 89%, getting at least half of the answers correct i.e. far higher than normative data would suggest (Sullivan & Waugh, 2005). This may show the impact of the stroke information received as inpatients by this group, or may reflect a group with a higher level of education than those in the normative data study (Sullivan & Waugh, 2005).

Table 38: Stroke knowledge test scores

| Pseudonym | Pre ASPIRE Stroke Knowledge Test scores | Post ASPIRE Stroke Knowledge Test scores |
|-----------|---|--|
| Alan | 13 | 14 |
| Clara | 13 | No data |
| Cyril | 14 | 13 |
| Dick | 17 | 20 |
| Dan | 16 | 15 |
| Derek | 12 | 16 |
| Hetty | 10 | No data |
| Kate | 10 | 20 |
| Jack | 14 | 13 |
| Jeff | 13 | 18 |
| Jenny | 10 | 17 |
| Lionel | 16 | No data |
| Marjorie | 8 | 13 |
| Penny | 10 | 13 |
| Richard | 9 | 13 |
| Sarah | 15 | 17 |
| Simon | 11 | 18 |
| Vanessa | 16 | 19 |
| William | 10 | 16 |

As detailed in table 38, and illustrated in figures 6 and 7, a marked improvement in stroke knowledge was demonstrated between initial and final questionnaires. After attending the ASPIRE programme, 13 out of the 16 stroke survivors improved their scores, with 10 out of 16 now getting at least three-quarters

correct. Not everyone's scores improved; however, although Cyril, Dan and Jack's scores only decreased by one point and every participant, after attending the ASPIRE programme, got a score of at least 13 out of 20.

Figure 6: Stroke Knowledge Test scores

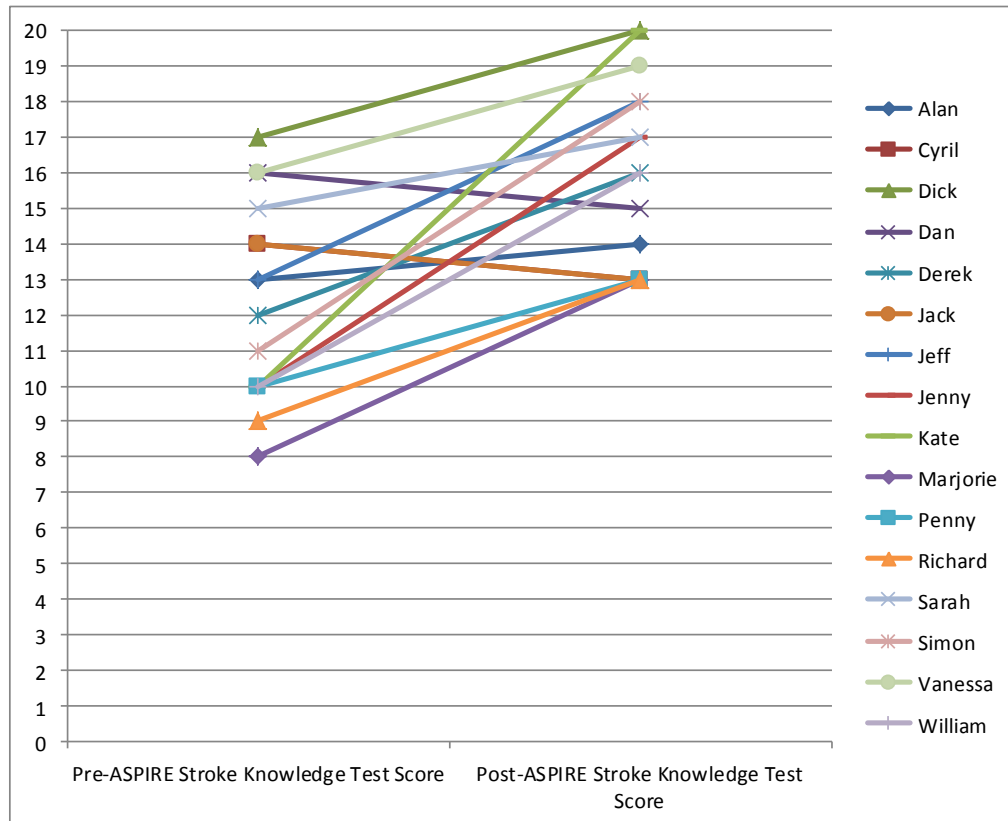


Figure 6: Pre-ASPIRE and Post-ASPIRE Stroke Knowledge Test scores for individual participants.

Stroke knowledge test statistics

As this is ordinal data, median scores plus inter-quartile range are shown in table 39, and illustrated in figure 7. Using a Wilcoxon test on the data (T=7.5, N=16), the results were found to be significant at <0.005 for a one tailed test.

Table 39: Stroke knowledge test statistics

| Statistic | Median | Inter-quartile range |
|--------------------|--------|----------------------|
| Pre-ASPIRE scores | 12 | 4 |
| Post-ASPIRE scores | 16 | 5 |

Figure 7: Stroke knowledge test statistics

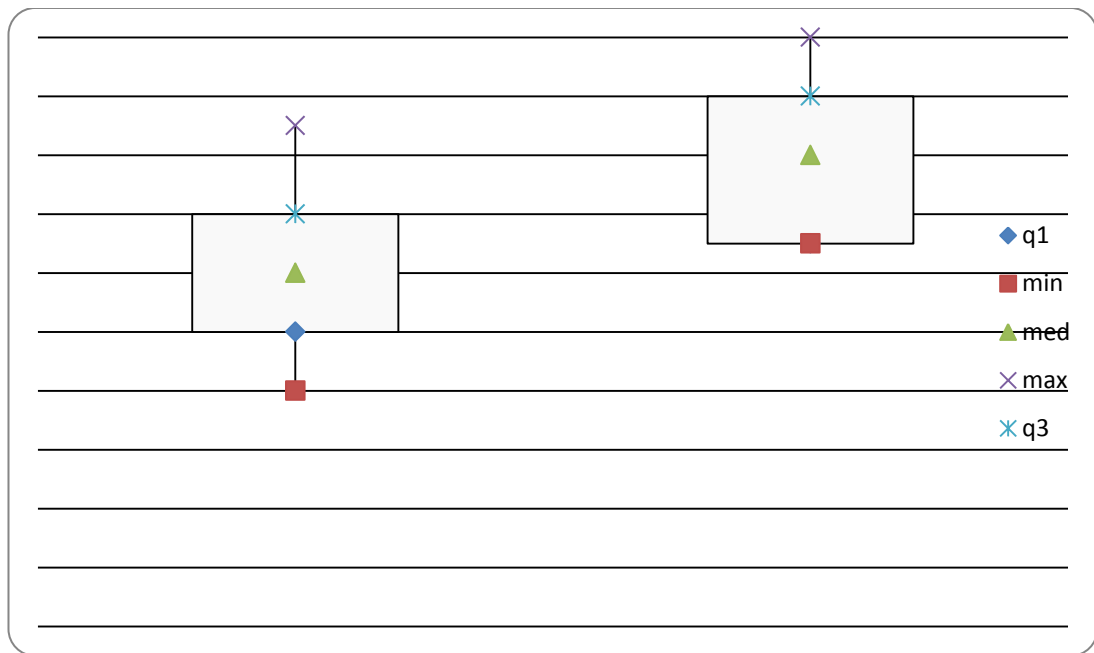


Figure 7: Pre- and Post-ASPIRE median SKT scores (med) plus lower quartile (q1), upper quartile (q3), and inter-quartile range.

Analysis of findings - Stroke Knowledge Test

It should be noted that as all participants were given their final set of questionnaires to complete at their last attendance at ASPIRE, and most took several weeks to return the questionnaires, often bringing them to a review appointment, usually one month after completing the 12 week ASPIRE programme, there was variability and lack of clarity, in how long, the increased knowledge demonstrated, had been retained for. In addition, as the Stroke Knowledge Test was completed, at home, unsupervised, both pre- and post-ASPIRE, it is possible that the initial high scores and significant improvement in scores post-ASPIRE, compared with pre-ASPIRE, was due to participants having the opportunity to look up the correct answers, or being told the correct answer by a family member. To prevent this, participants could have been asked to complete the follow up Stroke Knowledge Test at their review appointment.

Hospital Anxiety and Depression Scale - Anxiety

The Hospital Anxiety and Depression Scale scores, in terms of anxiety, for all participants before attending the ASPIRE programme, are detailed in table 40.

Figure 8 illustrates the anxiety scores for the 16 participants for whom data from before and after attending the ASPIRE programme is available. Scores of between 8 and 10 out of 21 indicates *possible* anxiety, whereas scores of 11 or more out of 21 indicates *probable* anxiety.

Table 40: Hospital Anxiety and Depression Scale (HADS) – Anxiety scores

| Pseudonym | Pre ASPIRE HADS score - anxiety | Post ASPIRE HADS Score- anxiety |
|-----------|---------------------------------|---------------------------------|
| Alan | 7 | 11 |
| Clara | 18 | No data |
| Cyril | 5 | 6 |
| Dick | 6 | 8 |
| Dan | 8 | 10 |
| Derek | 16 | 16 |
| Hetty | 0 | No data |
| Kate | 2 | 2 |
| Jack | 3 | 1 |
| Jeff | 13 | 4 |
| Jenny | 5 | 5 |
| Lionel | 3 | No data |
| Marjorie | 9 | 3 |
| Penny | 4 | 4 |
| Richard | 1 | 3 |
| Sarah | 14 | 11 |
| Simon | 5 | 6 |
| Vanessa | 2 | 2 |
| William | 17 | 17 |

It can be seen that of the 19 participants for whom there is initial data, five were assessed as probably anxious, and a further two as possibly anxious, before attending the ASPIRE programme. Of the 16 participants for whom there is data for after attending the ASPIRE programme, there is significant variability in scores, both before and after, attending the ASPIRE programme. There is also no clear group pattern in whether scores increased, decreased or stayed the same; however, two of the 16 participants after attending APIRE were now assessed as probably anxious, and four of the 16 were assessed as possibly anxious.

Figure 8: Hospital Anxiety and Depression Scale (HADS) – Anxiety scores

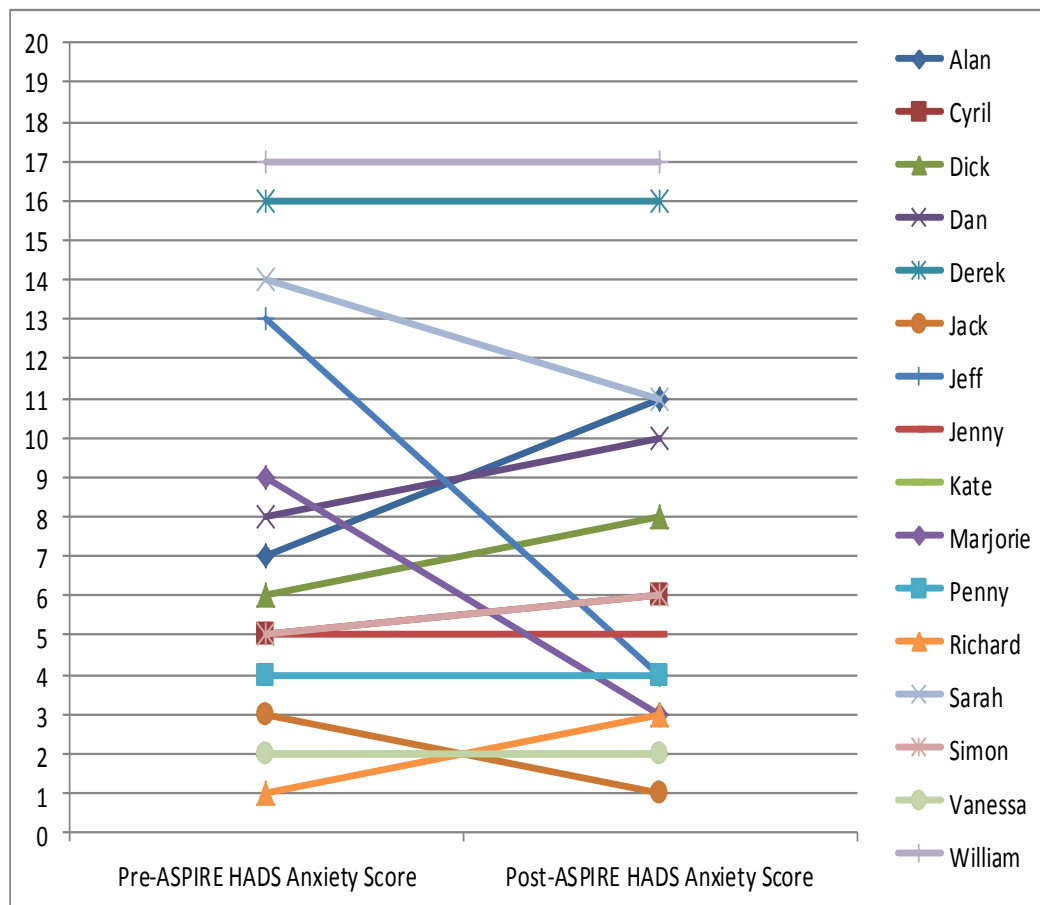


Figure 8: Pre-ASPIRE and Post-ASPIRE HADS anxiety scores for individual participants.

Hospital Anxiety and Depression Scale – Anxiety – statistics

As can be seen, the majority of the group are not anxious, either before or after attending the ASPIRE programme, and for the group as a whole, there is no real change. Although there is marked variation in individual anxiety scores, the HADS anxiety subscale is able to assess all of these, with no apparent floor or ceiling effect. As this is ordinal data median scores plus interquartile range are shown in table 41, and illustrated in figure 9. Using a Wilcoxon test on the data ($T = 24.5$, $N = 10$), the results were found to be non-significant for a one-tailed test.

Table 41: Hospital Anxiety and Depression Scale (HADS) – Anxiety statistics

| Statistic | Median | Inter-quartile range |
|--------------------|--------|----------------------|
| Pre-ASPIRE scores | 5 | 6 |
| Post-ASPIRE scores | 5 | 7 |

Figure 9: HADS anxiety scores – statistics

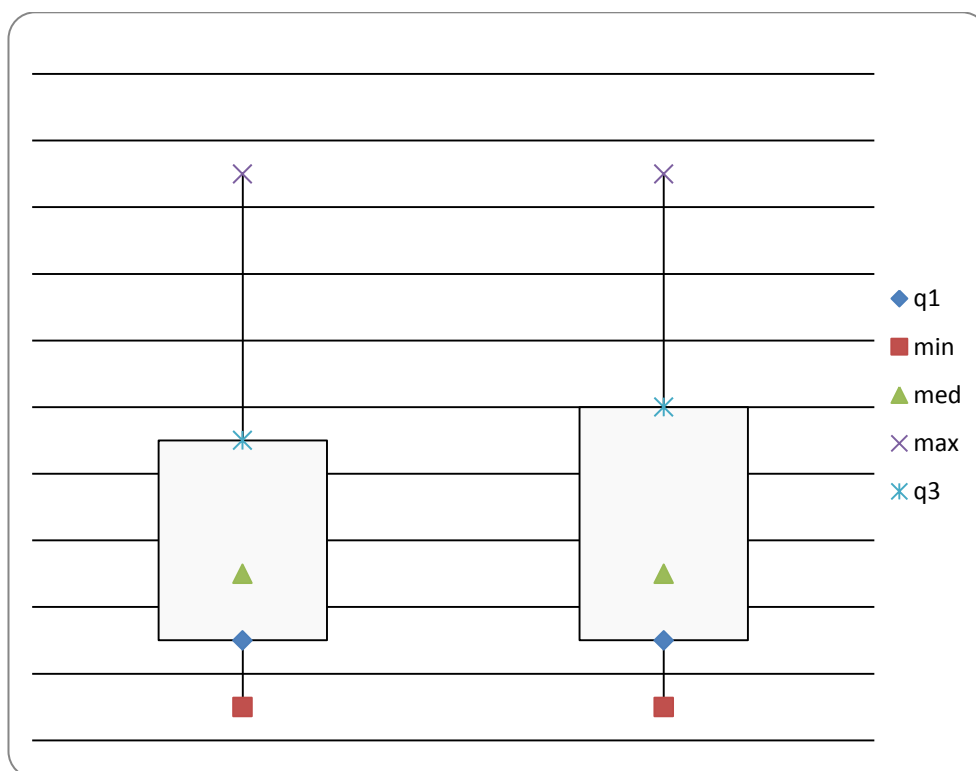


Figure 9: Pre-and Post-ASPIRE median HADs Anxiety score (med), lower quartile (q1) and upper quartile (q3) and inter-quartile range .

Analysis of findings - Hospital Anxiety and Depression Scale – Anxiety

As detailed in table 4, and illustrated in figure 9, individual variability, as shown by the large inter quartile range, makes it difficult to see a clear trend in anxiety levels, and the differences are small for most individuals. Although two participants (Marjorie and Jeff), were markedly less anxious, at the end of ASPIRE, compared with beforehand, many scores stayed the same, and anxiety scores increased in six out of 16 participants, so some participants may be more anxious after completing ASPIRE, than before. Alan's score increased markedly from 7 (not anxious) to 11 (probable anxiety). Without asking Alan it is difficult to be certain, but his increased anxiety may well relate to the development of leg pain, initially thought to be due to gout, and then under investigation as being due to an ischaemic cause. For others, the increase in anxiety may be due to the timing of the completion of the second set of questionnaires, just as people are finishing the ASPIRE programme, and experiencing uncertainty about the future, without the support of ASPIRE. It is clear from phase 1 interviews that although many

participants felt the programme was the right duration, it was also evident that not all participants were ready to move on from ASPIRE after 12 weeks.

In contrast, the positive change for some individuals was even more marked; Jeff's score went down from 13 (probable anxiety) to 4 (not anxious); and Marjorie's score went from 9 (possible anxiety) to 3 (not anxious). These decreases in anxiety scores may be due to a number of factors including; the peer and / or professional support and reassurance provided by the ASPIRE programme; increases in knowledge about stroke; or recovery from impairments allowing a return to previous functional levels. Time passing since the stroke may also be a factor, as anxiety levels can decrease over the first 6 months after stroke in up to 40% of people, irrespective of the rehabilitation input received (De Wit et al, 2008).

Hospital Anxiety and Depression Scale – Depression

The Hospital Anxiety and Depression Scale scores, in terms of depression, for all participants, before attending the ASPIRE programme, are detailed in table 42. Figure 10 illustrates the depression scores for the 16 participants, for whom data from before and after attending the ASPIRE programme, are available. Scores of between 8 and 10 out of 21 indicates *possible* depression, whereas scores of 11 or more out of 21 indicates *probable* depression. It can be seen that of the 19 participants for whom there is initial data, two are assessed as probably depressed and a further three as possibly depressed, before attending the ASPIRE programme.

Of the 16 participants, for whom there is data for after attending the ASPIRE programme; there is no clear group pattern in whether scores have increased, decreased or stayed the same. None of the 16 participants are probably depressed, and only three of the 16 are possibly depressed after attending ASPIRE. For two individuals; however, there was a marked positive change; William's score went from 15 (probable depression) to 10 (possible depression), and Jeff's score went from 9 (possible depression) to 1 (not depressed).

Table 42: Hospital Anxiety and Depression Scale (HADS) – Depression scores

| Pseudonym | Pre ASPIRE HADS score - depression | Post ASPIRE HADS Score- depression |
|-----------|------------------------------------|------------------------------------|
| Alan | 3 | 3 |
| Clara | 11 | No data |
| Cyril | 4 | 5 |
| Dick | 9 | 7 |
| Dan | 6 | 9 |
| Derek | 10 | 10 |
| Hetty | 3 | No data |
| Jack | 4 | 2 |
| Jeff | 10 | 2 |
| Jenny | 1 | 0 |
| Kate | 1 | 1 |
| Lionel | 4 | No data |
| Marjorie | 4 | 4 |
| Penny | 7 | 4 |
| Richard | 3 | 4 |
| Sarah | 6 | 5 |
| Simon | 2 | 0 |
| Vanessa | 2 | 1 |
| William | 15 | 10 |

Figure 10 Hospital Anxiety and Depression Scale (HADS) – Depression scores

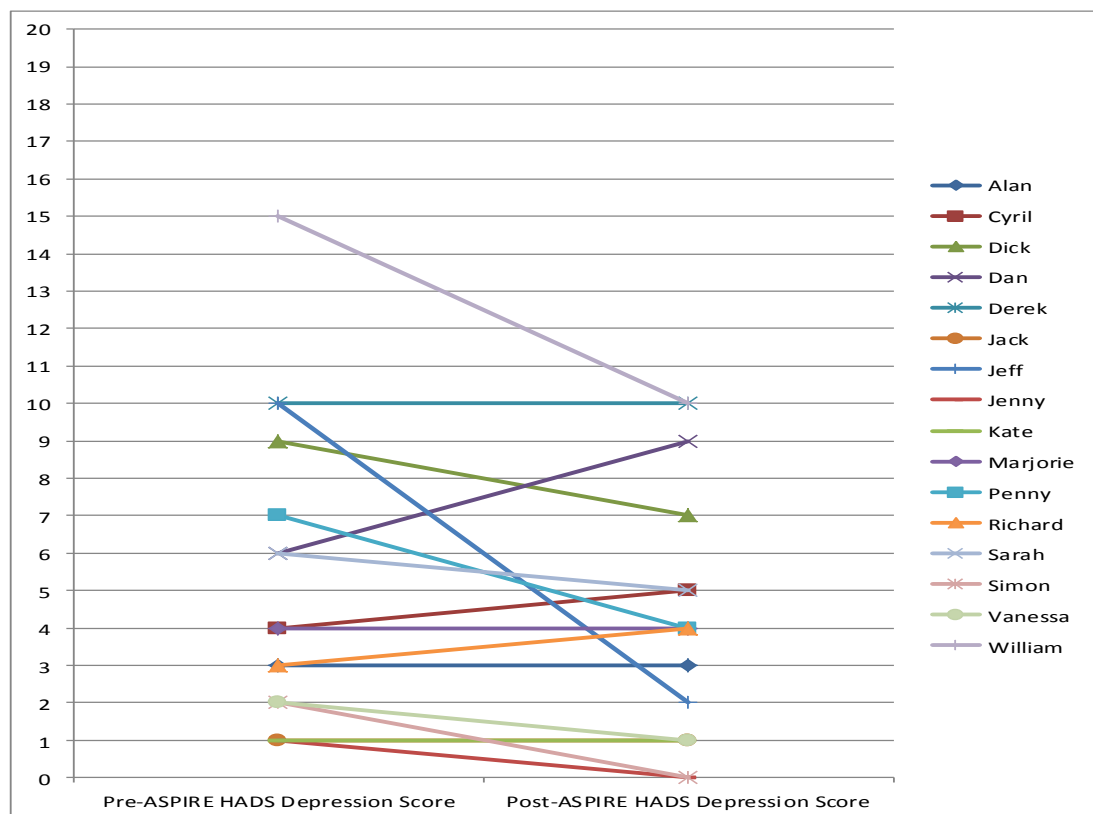


Figure 10: Pre-ASPIRE and Post-ASPIRE HADS depression scores for individual participants.

Hospital Anxiety and Depression Scale (HADS) Depression scores - statistics

The large inter-quartile range shown in table 43, and illustrated in figure 11, indicates that depression scores exhibited great variability, both before and after, attending the ASPIRE programme. As this is ordinal data, median scores plus interquartile range are shown in table 43 and illustrated in figure 11. Using a Wilcoxon test on the data (T=15.5, N=12), the results were found to be significant at <0.05 for a one tailed test.

Table 43: Hospital Anxiety and Depression Scale (HADS) Depression statistics

| Statistic | Median | Inter-quartile range |
|--------------------|--------|----------------------|
| Pre-ASPIRE scores | 4 | 6 |
| Post-ASPIRE scores | 4 | 6 |

Analysis of findings - Hospital Anxiety and Depression Scale - Depression

There was statistically significant reduction in depression, with 9 out of 16 having lower depression scores at the end, than the beginning, with two participants (William and Jeff) showing the greatest change. This finding may be due to the length of time since stroke and moving through the grieving process, rather than the impact of attending the ASPIRE programme; in line with the study by De Wit et al (2008), which found approximately 40% of those with initial depression, were no longer depressed at 6 months, irrespective of rehabilitation input.

Figure 11: HADS depression scores - statistics

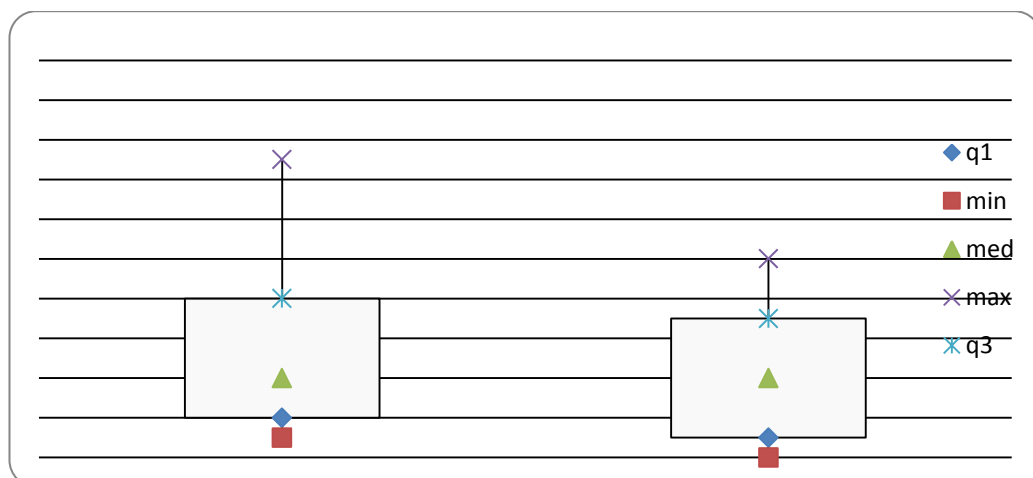


Figure 11: Pre- and Post-ASPIRE median HADS Depression scores (med), lower quartile (q1), upper quartile (q3) and inter-quartile range.

In addition to the issues already discussed, other factors completely unrelated to stroke or the ASPIRE programme, such as finances or family issues, may also have impacted on mood. Harrington et al (2010) found no statistical difference in levels of anxiety or depression in stroke survivors, after compared with before, attendance at a community exercise and education scheme. In hindsight, interviews with phase 2 participants, as well as completion of questionnaires, would have helped to understand more about the impact of other factors on mood. Overall the HADS has proven to be a useful assessment tool for identifying issues with anxiety and depression, and continues to be used routinely, with stroke survivors attending the ASPIRE programme, as it helps to raise awareness of mood as an issue, and can help with initiating a discussion on mood, at the first session.

Caregiver Strain Index

With only four complete sets of data, from the six initial participants, it is difficult to identify any trend in scores; therefore, descriptive data only are presented. The individual Caregiver Strain Index scores, before and after (where available) attending the ASPIRE programme, are presented in table 44 and illustrated in figure 12, using a 3-D graph to allow the zero scores to be seen. Three out of four caregivers had a lower score after attending the ASPIRE programme, which might indicate less caregiver strain; however, with such small numbers it is difficult to be certain.

Analysis of findings - Caregiver Strain Index

Although there was a reduction in Caregiver Strain Index for most respondents, as there were only four complete sets of data from caregivers, as shown in table 44, it is difficult to identify a trend, and although reductions in Caregiver Strain are seen in 3 out of 4 caregivers, this may be due to time since stroke, rather than due to the ASPIRE programme. With so little data, it is also unclear whether the Caregiver Strain Index is a good 'fit' for the impact of ASPIRE on caregivers. Much richer data on the impact of the ASPIRE programme, on both stroke survivors and caregivers, comes from the interviews in phase 1.

Figure 12: Caregiver Strain Index Scores

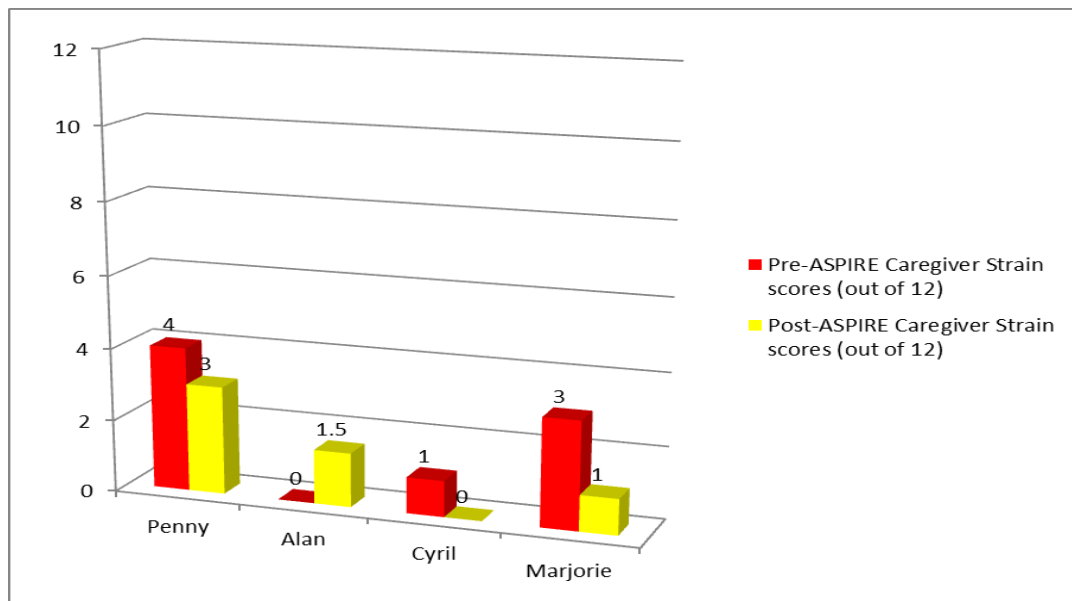


Figure 12: Pre-ASPIRE and Post-ASPIRE Caregiver strain index scores for individual participants.

Table 44: Caregiver Strain Index

| Carer of Stroke Survivor | Pre ASPIRE Caregiver Strain Index score (out of 12) | Post ASPIRE Caregiver Strain Index score (out of 12) |
|--------------------------|---|--|
| Penny | 4 | 3 |
| Alan | 0 | 1.5 |
| Cyril | 1 | 0 |
| Marjorie | 3 | 1 |
| Hetty | 3 | Not returned |
| Jack | 1 | Not returned |

4.9 Pragmatically collected measures

From the beginning, all participants in the ASPIRE programme have had physiological measures, such as their blood pressure and weight, routinely and pragmatically collected, at most attendances. As the vast majority of ASPIRE participants have a history of hypertension and / or atrial fibrillation, blood pressures are measured ,at each session, using a manual auscultatory device, as recommended for those with hypertension and or atrial fibrillation (Skirton et al, 2011). The same device was used each time, with participants in sitting, and the procedure mostly carried out, as per European Hypertension Society recommendations (O’Brien et al, 2003); however, rarely do the participants have 5 minutes relaxed in sitting, with no conversation prior to, and during

measurement, as they are usually sat chatting to each other, whilst waiting for their turn. Pulses are usually taken, alongside blood pressures, though not recorded unless an abnormality is identified. Despite having had the usual investigations shortly after their stroke, a few ASPIRE participants have had an irregular heart rate recognised for the first time at the ASPIRE programme, and then been referred for further investigations.

Weight in kilogrammes is measured using standard step on scales. As the programme has developed, and subsequent to feedback and further reading, abdominal obesity (waist girth) and body mass index (BMI) have also been captured, at the first and last sessions, for many participants, since 2009. ‘Gwen’, an ASPIRE participant not involved in the research, inspired the introduction of waist girth measurements. ‘Gwen’ was indignant that her efforts to lose weight, failed to register on the scales, and insisted that her clothes were looser. The use of girth measurements has a robust evidence base to support them, as abdominal obesity is known as an independent risk factor for primary stroke (Winter et al, 2008; Lu et al, 2006). For those who are overweight or obese, girth (i.e. abdominal obesity) is routinely measured, at initial and final appointments, using a tape measure to measure girth at the central abdomen i.e. the largest part. BMI is calculated from patients’ height, and measured weight, and is monitored not only in those overweight, but also in those who are underweight, or who have lost weight, either whilst an inpatient early after stroke, usually due to an impaired swallow and the need for enteral feeding, or due to other comorbidities.

Changes in physiological measurements were not an anticipated outcome for phase 2 of the research, as the focus was on participants views of the outcomes from the ASPIRE programme. The data are presented; however, as the consent form signed by participants had been developed prior to phase 1, so was intended to cover all potential outcomes, including self-completion of questionnaires, and objective assessments carried out by a clinician. As blood pressure was not an anticipated outcome from phase 2, although initial anti-hypertensive use was recorded, no systematic record was kept of adjustments to medication by general practitioners, which may have affected blood pressures. In addition, as weight and

girth were not planned outcomes from phase 2, no record was kept of primary care dietetic input, that may have had an impact.

Available physiological data, for those participating in phase 2 of the research, are presented in table 45, and give an indication of the variety in body types, and blood pressure levels of those participating in the study. It should be noted that this data is incomplete, as it was collected pragmatically and routinely in the clinical setting, rather than in a standardised way. No weight could be recorded for William at his initial appointment, due to his poor balance and thus inability to use the step-on scales. No sit-on or hoist scales are available in the clinic setting, however those with poor balance are not excluded from the ASPIRE programme, as they can participate in appropriate activities to improve their balance. As can be seen William was able to use the step-on scales by the end of the programme.

Table 45: Physiological measures

| Pseudonym | Initial BP mmHg | Final BP mmHg | Initial Weight Kg | Final Weight Kg | Initial Girth ” / BMI | Final Girth ” / BMI |
|------------------|------------------------|----------------------|--------------------------|------------------------|------------------------------|----------------------------|
| Alan | 115/74 | 112/65 | 97.0 | 96.7 | NR | NR |
| Clara | 160/85 | NR | 83.5 | NR | NR | NR |
| Cyril | 130/84 | 120/66 | 85.5 | 87.3 | NR | NR |
| Dick | 135/82 | 118/80 | 79.9 | 81.5 | N/R | N/R |
| Dan | 115/78 | 138/98 | 92.2 | 95.1 | N/R | 40.5” / 31 |
| Derek | 142/80 | 130/75 | 79.2 | 79.5 | NR | NR |
| Hetty | 114/76 | NR | 55.7 | NR | NR | NR |
| Kate | 134/71 | 142/84 | 72.2 | 65.8 | 26.5 | 25.0 |
| Jeff | 138/90 | 118/70 | 91.5 | 89.7 | NR | NR |
| Jack | 130/72 | 160/75 | 120.0 | 120.6 | 52” | 49” |
| Jenny | 125/70 | 120/80 | 71.5 | 69.0 | 34” | NR |
| Lionel | 104/64 | NR | 76.4 | NR | NR | NR |
| Marjorie | 110/70 | 127/74 | 51.3 | 51.0 | NR | NR |
| Penny | 132/60 | 110/60 | 71.5 | 70.1 | NR | NR |
| Richard | 112/66 | 100/60 | 94.2 | 94.6 | 43” / 31 | 30 |
| Sarah | 140/80 | 135/78 | 112.0 | 109.3 | 51” | 49” |
| Simon | 142/98 | NR | 77.1 | NR | 39” / 27 | NR |
| Vanessa | 122/78 | 146/88 | 77.8 | 79.2 | 38” / 29 | NR |
| William | 92/50 | 102/50 | NR | 101.2 | NR | NR |

Blood pressure

It can be seen that from table 45, that the vast majority of systolic and diastolic blood pressures recorded are at, or below, target levels of 130/80 mm Hg (Intercollegiate Stroke Working Party, 2012), at the initial, and also at the final attendance at the ASPIRE programme. As shown in figures 13 – 18, there was no overall trend, in either systolic or diastolic blood pressure detected, at the final compared to the initial ASPIRE session, for those participants with complete blood pressure data sets. In eight of the 15 participants, systolic blood pressure decreased, and in nine of the 15 participants, diastolic blood pressure decreased or stayed the same. In the remaining participants, systolic and / or diastolic blood pressure increased. In contrast, despite a sizeable 10 mm Hg increase in systolic blood pressure, ‘William’ remained hypotensive. For all participants, blood pressure was only measured once at each clinic visit.

Figure 13: Systolic blood pressure measurements Pre and Post ASPIRE programme

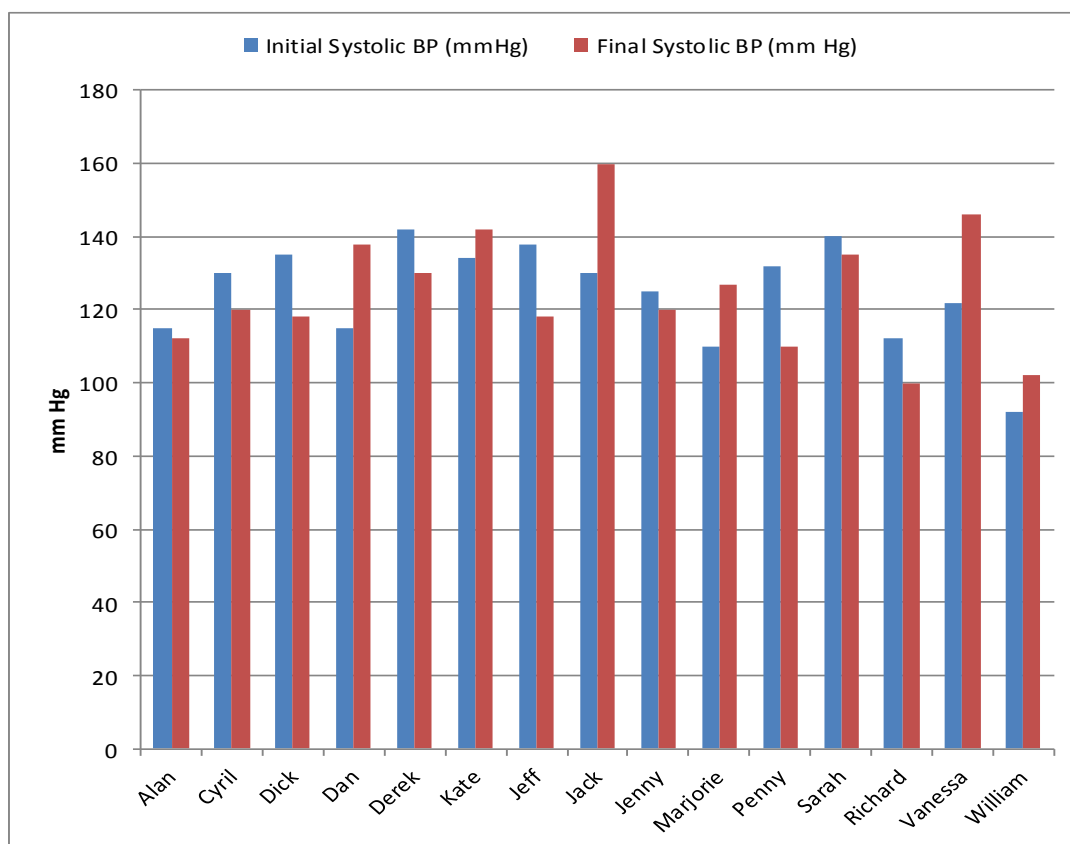


Figure 14: Systolic blood pressure changes Pre and Post ASPIRE programme

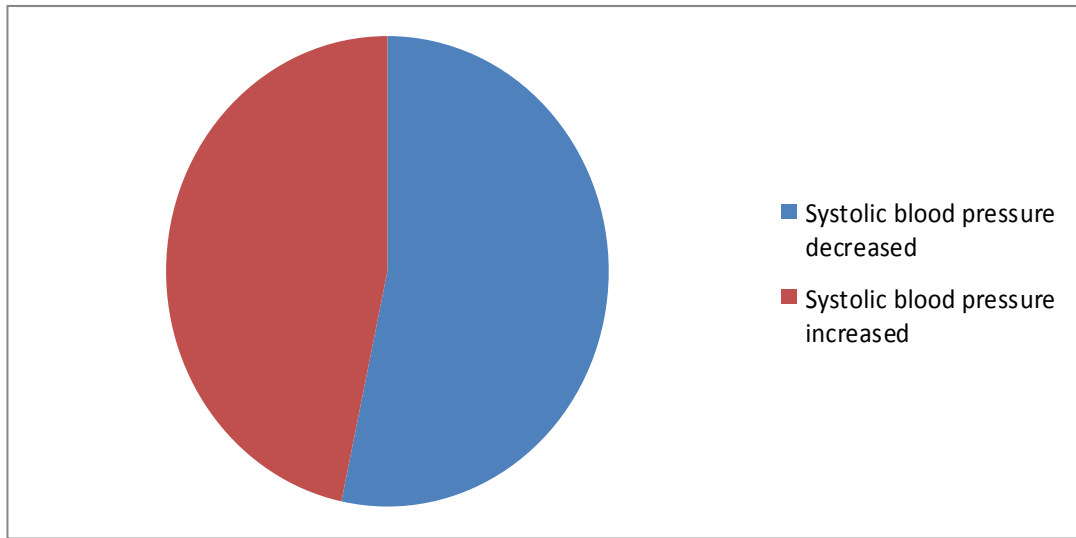


Figure 14: Systolic blood pressure decreased in 8/15 (53.3%) of participants and increased in 7/15 (46.7%) of participants.

Figure 15: Mean Systolic blood pressure Pre and Post ASPIRE programme

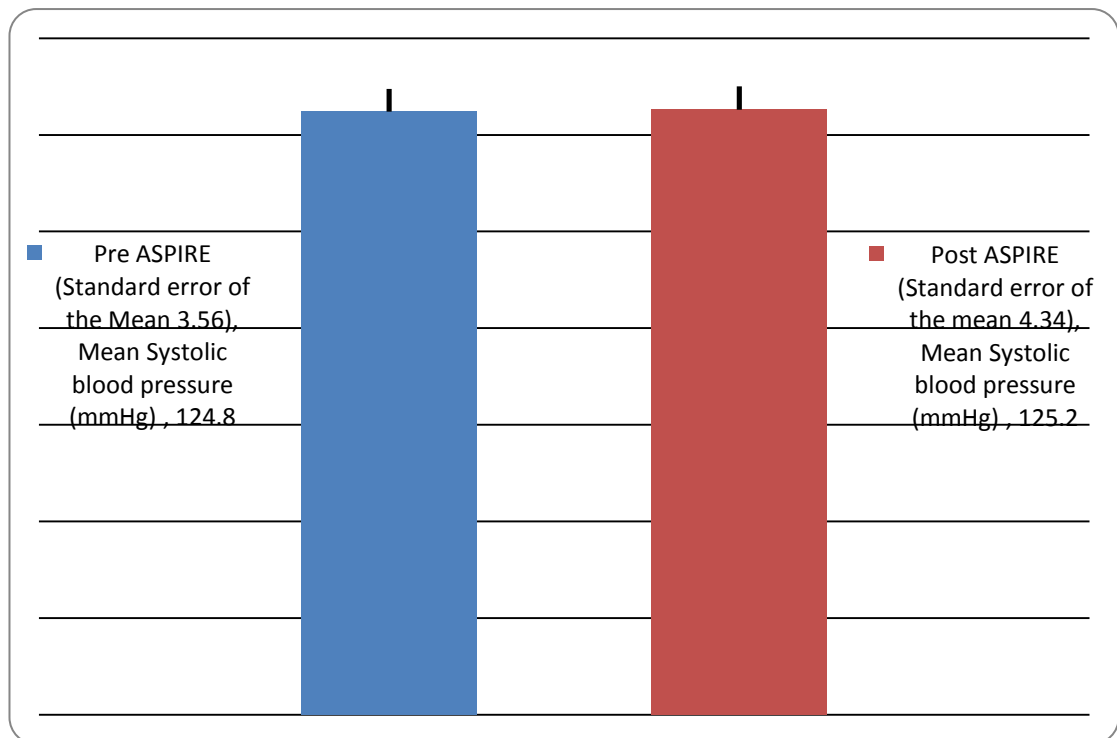


Figure 15: The columns represent the mean systolic blood pressure (124.8 mmHg Pre-ASPIRE and 125.2 mm Hg Post-ASPIRE). The T-bars represent the standard error of the mean (3.56mm Hg Pre-ASPIRE and 4.34mm Hg Post-ASPIRE).

Figure 16: Diastolic blood pressure measurements Pre and Post ASPIRE programme

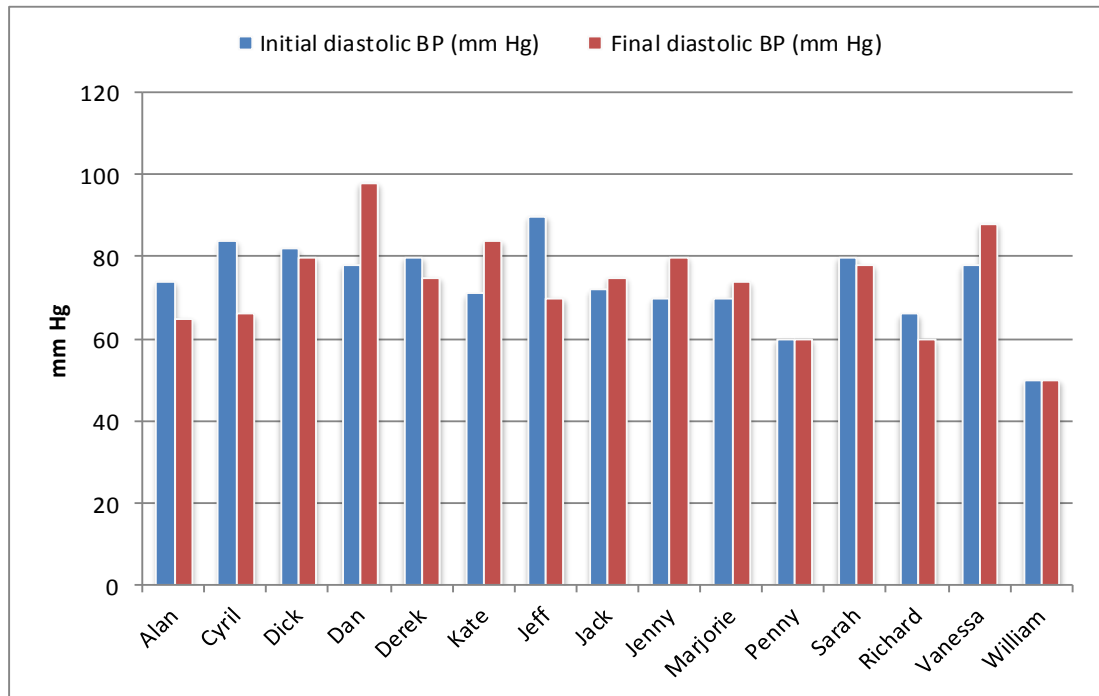


Figure 17: Diastolic blood pressure changes Pre and Post ASPIRE programme

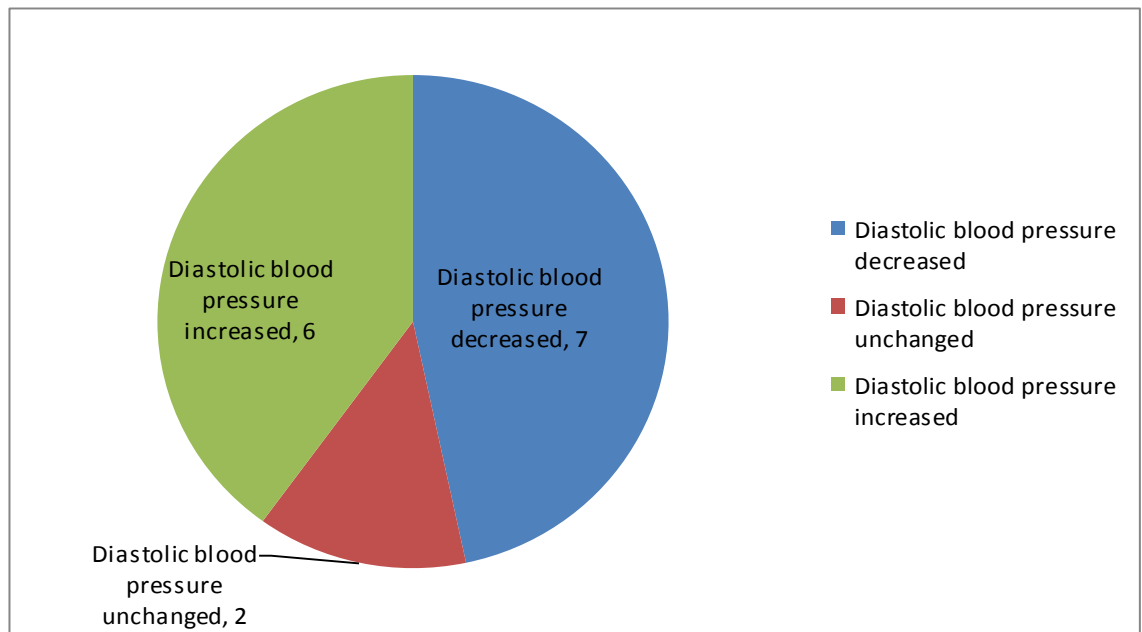


Figure 17: Diastolic blood pressure decreased in 7/15 (46.7%) of participants, increased in 6/15 (40%) of participant and remained unchanged in 2/15 (13.3%) of participants.

Figure 18: Mean Diastolic blood pressure Pre and Post ASPIRE programme

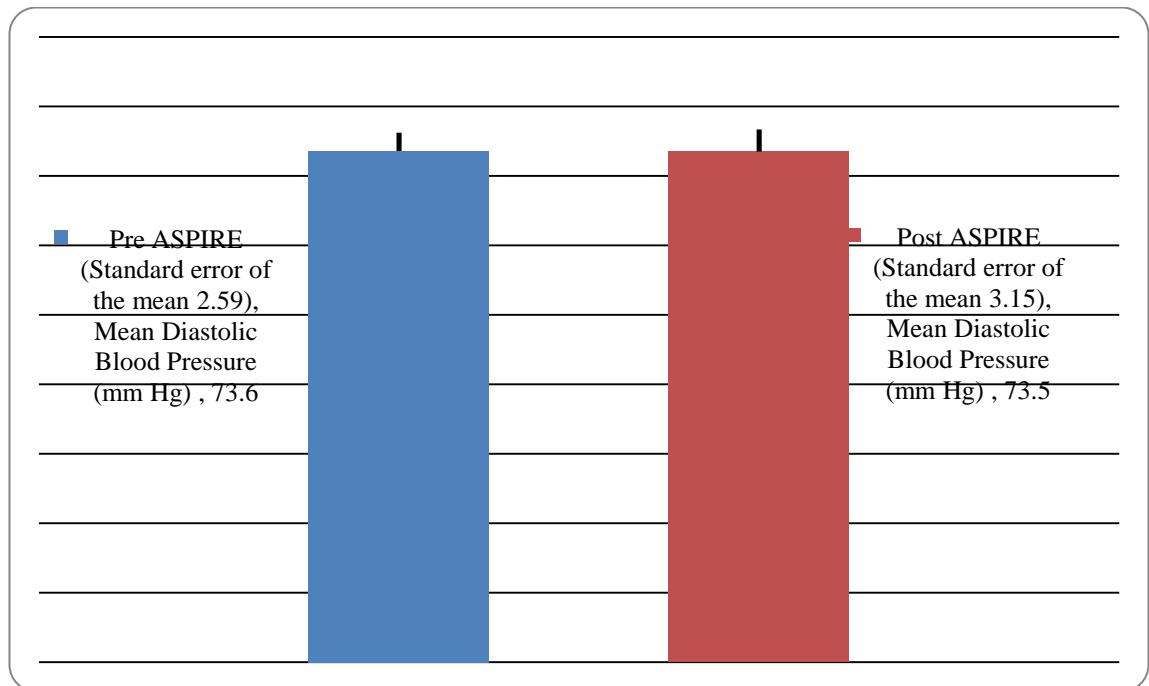


Figure 18: The columns represent the mean diastolic blood pressure (73.6 mmHg Pre-ASPIRE and 73.5 mm Hg Post-ASPIRE). The T-bars represent the standard error of the mean (2.59mm Hg Pre-ASPIRE and 3.15mm Hg Post-ASPIRE).

Analysis of findings – blood pressure

The lack of consistent change in blood pressures overall, could be considered surprising, as reductions in systolic and diastolic blood pressure have previously been demonstrated over the course of a 12 week exercise programme (Jorgensen et al, 2010); however, this programme was five times, rather than once per week, and blood pressures were recorded in a standardised way. The lack of consistent change, demonstrated in the current study, may be due to alterations in blood pressure medication by the participants doctor (which was not recorded), or may be due to the lack of standardisation in capturing those blood pressures, as it was not a planned outcome from the study. As shown in figures 15 and 18, the mean systolic and diastolic blood pressures, both before (124.8/73.5 mm Hg), and after (125.2/73.6 mm Hg) ASPIRE, were well within the target range of 130/80 mm Hg or less, so were already well controlled, making positive change less likely.

Experience shows, that for the vast majority of participants, routine monitoring of blood pressure, each week at the ASPIRE programme; will demonstrate

variability rather than any definite trend. For many participants, blood pressure gradually reduces; though, whether as a consequence of weight reduction, increases in cardiovascular fitness, changes in medication, or a reduction in ‘white coat syndrome’ as they become increasingly familiar with the gym environment; cannot be determined. For a few participants, blood pressure remains high and alterations to medications are needed. All participants; however, gain a greater understanding of what their blood pressure is, what it should be, how it varies and what factors (such as a stressful journey or difficulty finding a parking space), may affect their blood pressure.

Weight

The weights for participants, as recorded on bathroom scales, are listed in table 45, and illustrated in figures 19 and 20. It can be seen from figure 19, that there was a small decrease in weight in seven of the 14 participants with complete weight data, and a slight increase in weight in the remaining seven participants. Without also having information about participants’ girth and / or BMI, it is difficult to know in retrospect, whether participants were overweight or of normal weight. It can be seen from figure 20 that despite the variability there was a slight decrease in mean weight of 1.2kg, in the 14 participants with complete data.

Figure 19: Weight measurements Pre and Post ASPIRE programme

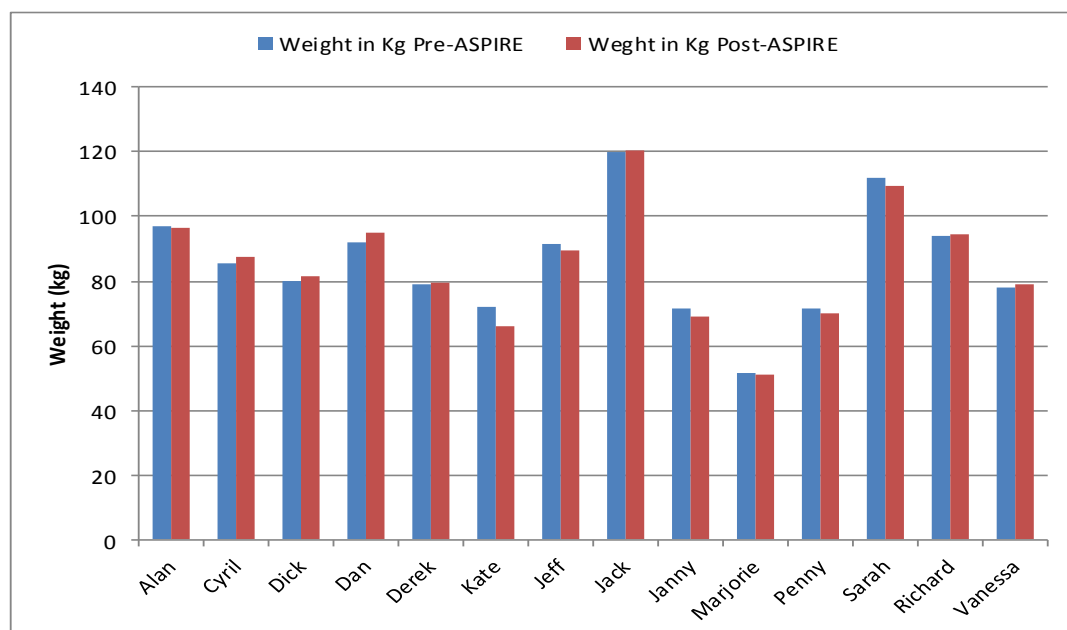


Figure 20: Mean weight Pre and Post ASPIRE

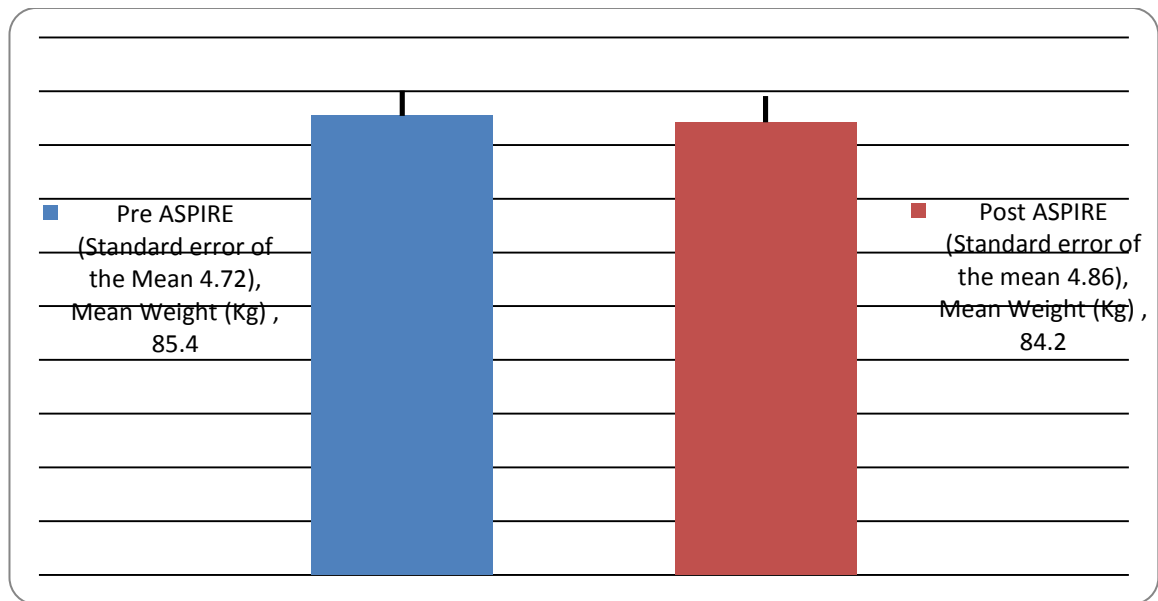


Figure 20: The columns represent the mean weight (85.4Kg Pre-ASPIRE and 84.2Kg Post-ASPIRE). The T-bars represent the standard error of the mean (4.72Kg Pre-ASPIRE and 4.86Kg Post-ASPIRE).

Statistical analysis

Statistical analysis of this result, using a student t-test and a one tailed hypothesis, gives a t value of 0.92 which is not statistically significant.

Analysis of findings - weight

A 5% weight loss can realistically be achieved, over a 12 week period, for those overweight or obese i.e. a BMI of >25 and < 40 (Varady et al, 2011). Among the 14 participants in phase 2 with complete data sets, as can be seen in table 46, only one (Kate) lost a significant amount of weight, approximately 10% of her body weight, over the 12 week ASPIRE programme, bringing her BMI down from 26.5 (overweight) to 25 (normal weight). Others only lost a small amount of weight or none at all.

Jack and Sarah in phase 2, were the only participants to have girth measured both at the start and at the finish of ASPIRE; Jack had lost girth without losing any weight, 3” from his waist. Similarly Sarah had lost 2” from her girth with only a modest weight loss. This may be due to an increased proportion of relatively

heavy muscle tissue in relation to adipose tissue, or due to measurer error; however, girth loss without significant weight loss, has also been observed in the clinic situation, in other ASPIRE participants.

PDSA 5: Act

Greater experience in the use of these assessment tools has been gained, outside of the phase 2 evaluation, as part of the on-going practice development project; giving further insights into the appropriateness of the assessment tools, with the participants in the ASPIRE programme. The ongoing use of the assessment tools is discussed below. In addition, the current format of the ASPIRE programme, and a summary of data from the 6 years and five PDSA cycles of the practice development project, are presented.

Outcome tools

Once phase 2 of the research study was underway, a decision was needed as to which outcome tools to continue to use in routine practice. Despite the **Stroke Knowledge Test** being a useful tool for the phase 2 study, the value in terms of secondary prevention to stroke survivors, of knowing the answer to some questions is questionable; for instance Question 14; *'how many people in the United Kingdom are affected by stroke each year?'*. In addition, an increase in knowledge about stroke does not necessarily lead to changes in behaviour that might reduce the risk of further stroke. The Stroke Knowledge Test is therefore not used routinely in practice, as it felt more important firstly to focus on each individual's gaps in knowledge, relevant to their own particular circumstances; whether that is being uncertain of what type of stroke they had; what the purpose of each medication is; or what to do about returning to work; and secondly to support that individual to make and carry out an action plan, designed to reduce their risk of further stroke.

It was decided to routinely include two of the questionnaires used for phase 2, with the appointment letter to start ASPIRE. This decision was made, as it was noticed that participants who had completed the Cerebrovascular Attitudes and Beliefs scale (CABS-R) and Stroke Self Efficacy Scale questionnaires for the

research, appeared to arrive with a clearer idea of what they hoped to gain from attending the ASPIRE programme. It was also felt that these might provide valuable detailed information about participants' attitude to exercise (the CABS-R), and recovery from stroke (Stroke Self Efficacy Scale), at their first attendance. On average, just under half of the participants arrived, with these forms completed.

However, in addition to the inconclusive results found in phase 2 of the research, the **Cerebrovascular Attitudes and Beliefs Scale** – exercise subscale was soon found not to be a useful tool for those routinely attending the ASPIRE programme; as it is time-consuming to complete and analyse, and focuses only on one risk factor. Instead, the answer given to question 10 of the stroke self – efficacy scale (see Appendix 8a) “*How confident are you that you can do your own exercise programme every day?*” is often used to trigger an initial discussion with an individual about their attitudes to exercise, including; identifying physical, social and psychological barriers to exercise; beliefs about the benefits of exercise in relation to stroke risk; and understanding their previous experiences of exercise, in order to be able to support them, to become on-going exercisers post ASPIRE. This then leads on to an open discussion about the individual's beliefs about stroke risk, which may include other lifestyle risk factors such as weight, alcohol, smoking and stress management that are relevant to that individual, and may also include discussions about what a stroke is, what the purpose of the various investigations was, and why the various medications have been prescribed.

Informal feedback about the Cerebrovascular Attitudes and Beliefs Scale, from two non-research participants, also led the author to question the user-friendliness of the tool. The first was a young ASPIRE participant, with significant cognitive problems, who explained how frustrating she found it attempting to complete the scale, as she felt it was asking her the same thing over and over again; so much so that she reported that she had become extremely angry, screwed it up and threw it away. The second instance was a lady, who had visual field problems, so had been unable to complete the Cerebrovascular Attitudes and Beliefs Scale by herself, although keen to do so. As the questions were read out and her replies recorded, it

appeared that her view appeared to be influenced by completing the questionnaire; at the start she answered ‘no idea’ to questions about whether exercise would reduce her risk of stroke, and by the end was answering ‘I suppose it must do’. It is unclear whether lack of user-friendliness impacted on the results in phase 2 of the research, as this tool has not previously been used with a post-stroke population.

After a short while it was decided to use the Hospital Anxiety and Depression score (HADS), rather than the CABS-R, routinely with ASPIRE participants not involved with the research, as it was found participants engage in discussions about attitudes to exercise far more easily, than those about mood, particularly at their first session. Although initially it was a concern the HADS may be seen as intrusive, it has been well received and allows a discussion about mood to be initiated early in the first session. Overall, questionnaire completion rates have increased and now nearly every person arrives having completed the Stroke Self-Efficacy Scale and HADS; although, those with visual, cognitive and communication difficulties, who live alone, rarely bring them. Interestingly, it is not unusual, for those with cognitive problems, attending alone, to deny having received them.

As with the phase 2 research, routinely collected scores, on both the anxiety and the depression subscales of **The Hospital Anxiety and Depressions scale**, tend to be very variable; however, generally seem to be in line with the author’s clinical view of a person’s mood. The item, “I feel as if I am slowed down”, does tend to be rated as a 3 (= nearly all the time) very frequently, when all other depression scores are rated as 1 or 0. This is often due to physical, stroke impairment related slowing, rather than a mood related slowing down. Mood can often be a difficult subject to broach at a first meeting. Using the Hospital Anxiety and Depressions scale helps ASPIRE participants appreciate that mood is likely to be discussed, and prepare them for that. The Hospital Anxiety and Depressions scale is therefore used routinely.

Experience of continuing to use the **Stroke Self-Efficacy Questionnaire (SSEQ)** routinely in clinical practice, with non-research participants, has shown that as with the phase 2 research, although some have low initial scores, many ASPIRE programme participants are at, or near, the ceiling of the scale at their first attendance. This is in line with the findings of Jones et al (2008), who also found a ceiling effect, with those with greater mobility and independence in daily activities. For this type of participant, it is of no particular benefit, to repeat the questionnaire routinely, after they have completed the ASPIRE programme.

Interestingly, the author has noticed that some ASPIRE participants, particularly those with cognitive deficits, score themselves initially as ten out of ten, for each question in the Stroke Self-Efficacy Questionnaire, when objectively they are unable to successfully complete all the tasks; perhaps demonstrating a lack of insight or some lack of recognition of residual deficits. This is the type of participant who may arrive at their first session claiming to feel like a fraud, and perhaps also remaining unconvinced that they had had a stroke, as they are unaware of any deficits. A very different view often emerges from their caregivers, who may report issues with aspects such as mood, memory, concentration and behaviour. These participants often score themselves lower in the Stroke Self-Efficacy Questionnaire at the final session, as they have begun to have a more realistic view of their abilities.

In contrast, some routine ASPIRE programme participants report that they find some of the questions irrelevant, particularly if they have made a good overall recovery from their stroke. For this cohort, with often little or no residual deficits, (as shown by the ceiling effect in phase 2 of the research) the SSEQ is not aligned with the factors that this group of people with stroke considered to be most important in terms of their recovery from stroke; for instance the confidence to eat out in public, use a computer, return to driving or look after a grandchild. This indicates the need for an assessment tool, for this higher functioning group, that gives an indication of a stroke survivors' confidence in leading a life they like; with less of a focus on basic functions such as mobility, transfers, feeding and meal preparation.

For all those routinely attending ASPIRE, but especially those at or near the ceiling of the stroke self-efficacy scale, the SSEQ is less frequently used as a tool for assessing progress or outcome, and is more commonly used as a discussion trigger in the assessment session. For instance the answer provided to question 10 (see Appendix 8a); “*How confident are you that you can do your own exercise programme every day?*” is a useful discussion opener, particularly for those who have never previously exercised, or have been afraid to do so since their stroke. Similarly question 11 (see Appendix 8a); “*How confident are you that you can cope with the frustration of not being able to do some things because of your stroke?*” can start a dialogue about mood and relationships, in terms of whether caregivers prevent, allow or encourage the stroke survivor to return to previous activities. In a similar way question 12 (see Appendix 8a); “*How confident are you that you can continue to do most of the things you liked to do before your stroke?*” helps to identify what the individual has been able to return to, which enables him/her to acknowledge their progress so far, and also start to set some goals about further recovery from stroke. For those who have made a full recovery, it often allows them to highlight how fortunate they feel, compared with others who have had stroke, which is a useful point to start a discussion about secondary prevention.

For those routine ASPIRE programme participants, whose initial scores are low, information from their completed Stroke Self-Efficacy questionnaires, provides a useful way of quickly focussing on some of the participants’ remaining issues, at their first attendance. In addition, for those with lower scores, who usually have much greater residual impairment, repeating the Stroke Self-Efficacy Scale questionnaire, at the end of ASPIRE, helps them acknowledge their progress after three months. As with phase 2 of the research study, although the level of progress can be quite variable, those with the lowest initial scores tend to make the most progress. The process of repeating the questionnaire supports individuals to set specific on-going goals for further recovery, or identify the support they might need, including further rehabilitation input, or attending the Proactive exercise on prescription scheme. Overall, the Stroke Self-Efficacy Scale has proven to be a useful tool for assessment and for discussion, on initial attendance at ASPIRE, and for some, though not all participants, also at their last ASPIRE session. The Stroke Self-Efficacy Scale continues to be used routinely, at initial assessment, with all

ASPIRE participants, and also after attending the programme, with those not near the ceiling of the tool.

Rather than assessing health beliefs, using validated tools to demonstrate the positive impact of a change in health behaviours, appears to be of greater value, as it supports mastery, a key component of self-efficacy. Therefore the use of weighing scales, tape measure for girth, blood pressure monitor and 6 minute walk test for fitness, are now key aspects of the ASPIRE programme, though only blood pressure is measured weekly. Weight, girth and fitness are measured at first, last and review sessions, though are sometimes repeated at interim sessions, on request. Participants appear motivated by these quantitative measures, as a tangible way of acknowledging their initial situation, and of monitoring progress.

Overall, a useful tool would be one that assesses how 'ready, willing and able' a person is, to make and sustain the necessary lifestyle changes, and take the appropriate medication to reduce their risk of stroke. The Patient Activation Measure (Hibbard et al, 2004), which although not stroke specific, tested predominantly in diabetes, and only available under license appears to ask all the relevant questions may be appropriate for future clinical use.

A summary of the evaluation of all the assessment tools, that have been used in the ASPIRE programme routinely and/ or as part of the research, is presented in table 46.

Table 46: Summary evaluation assessment tools.

| <u>Standardised tool</u> | <u>Usability in this context</u> | <u>Comments</u> |
|--|--|---|
| Stroke Self-Efficacy Questionnaire (Jones et al, 2008) | Possible ceiling effect in this cohort, otherwise responsive to change. | No statistically significant improvements shown in phase 2 however trend towards self-efficacy in those who had attended ASPIRE programme. Is less relevant for those with better recovery from stroke. |
| Cerebrovascular Attitudes and Beliefs Scale (Exercise subscale) (CABS-R) (Sullivan & Waugh, 2007). | Possible ceiling effect in this cohort, otherwise responsive to change. Unable to distinguish between stroke and non-stroke related factors affecting attitudes to exercise. | Other subscales exist for other lifestyle factors such as weight loss. Not very user friendly to complete. |
| Stroke Knowledge Test (Sullivan & Dunton , 2004) | Responsive to change. No floor or ceiling effect noted in this cohort. | Statistically significant improvements shown in phase 2. Author's permission given to modify from Australian to English version. |
| Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). | Responsive to change. No floor or ceiling effect noted in this cohort. | Statistically significant improvements in depression though not anxiety shown in phase 2. One question 'I feel as if I am slowed down' appears to relate more to stroke impairment than mood. |
| Caregiver Strain Index (Robinson, 1983) | Appeared responsive to change. Possible floor effect. | Difficult to evaluate due to small numbers. |
| Systolic & diastolic blood pressure | Responsive to change however most of this cohort were normotensive prior to ASPIRE. | Collected pragmatically as part of routine clinical practice rather than in a standardised way. Can demonstrate the impact of health behaviour change. |
| Weight (Kg), Girth & BMI. | Responsive to change however the majority of this cohort was of normal weight, BMI and girth prior to ASPIRE. | Collected pragmatically as part of routine clinical practice. Can demonstrate the impact of health behaviour change. |

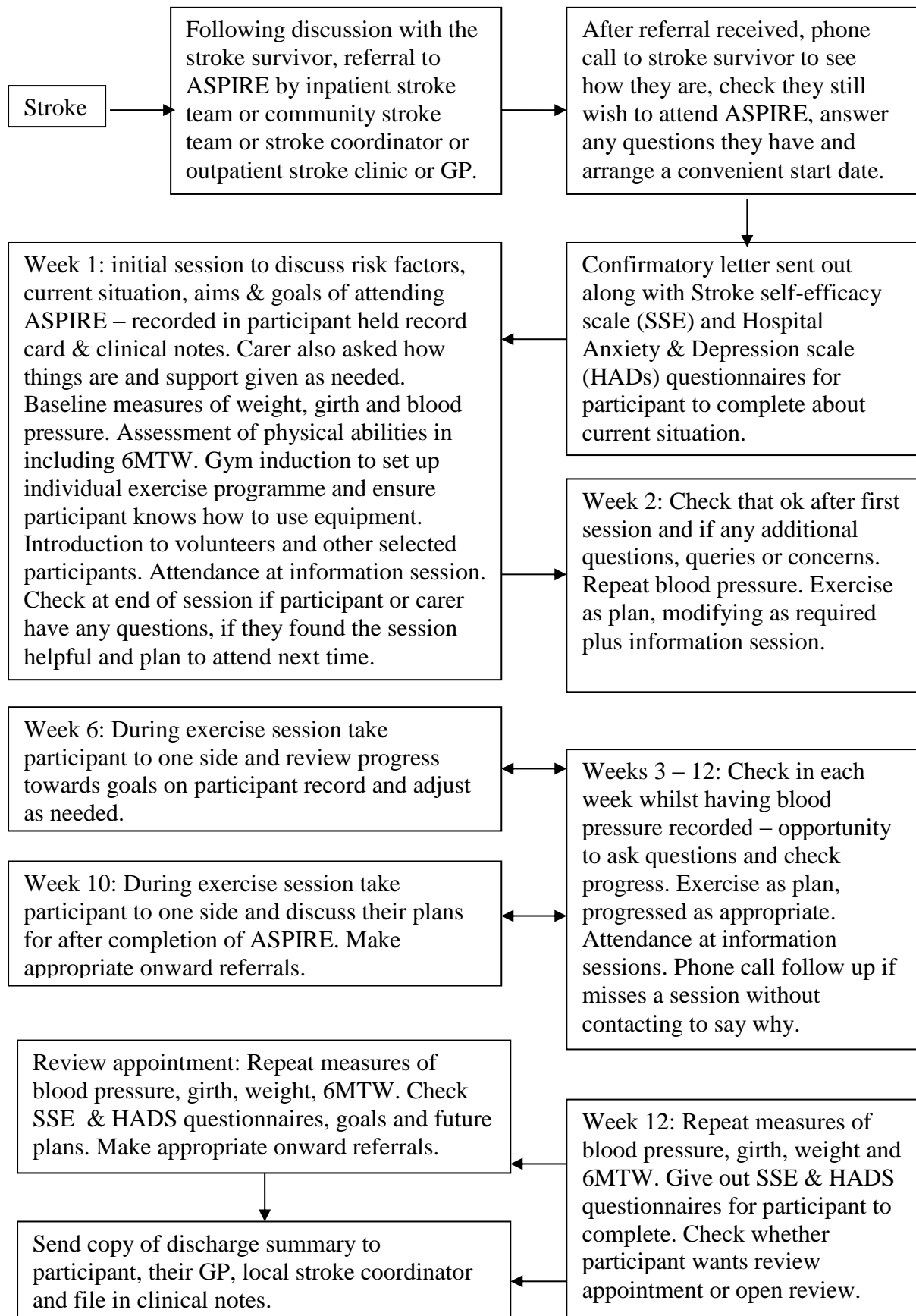
The current ASPIRE programme

It has been recommended that an intervention is described fully, with a standardised template to improve replicability using the TIDieR checklist (Hoffman et al, 2014); however, this requires an exact description of materials and procedures undertaken, rather than an individualised and person-centred approach. The current ASPIRE programme, is therefore detailed in table 47, using the same format as previously, and illustrated in figure 21.

Table 47: Current ASPIRE programme

| Component | ASPIRE |
|--------------------------|--|
| Assessment | Individual assessment & information session plus discussion about aims of attending programme in relation to recovery from stroke and also secondary prevention. Blood pressure, weight, BMI, waist circumference, confidence after stroke (Stroke Self-Efficacy Scale) (SSE), Mood (Hospital Anxiety & Depression Scale) (HADS) & 6 Minute Timed Walk (6MTW). |
| Participants | Up to about 30 adult stroke survivors and their caregivers of all ages. Most have mild to moderate residual impairments mostly of communication, cognition, sensation or upper limb movement. A small proportion use a wheelchair for mobility and may be hoisted or use a transfer aid and assistance to transfer or need assistance plus a gait aid to stand and are able to take a few steps at most. |
| Exercise session | Up to 60 minutes of individually tailored and progressed exercise including cardiovascular, balance and strengthening exercise in the large outpatient rehabilitation gym. Greater variety and numbers of exercise equipment. |
| Information session | 30 minutes interactive discussion held in seminar room – informal seating area with participants from both exercise sessions. Tea and coffee served by volunteer – dysphasic ex-ASPIRE participant. Information sessions as before though with volunteers both contributing to and leading sessions. |
| Supporting documentation | Patient held yellow ASPIRE card to record details about medication, risk factors, weight & blood pressure, recovery from stroke and secondary prevention goals plus exercise programme. |
| Overall staffing | Consultant therapist – rehabilitation, Rehabilitation assistant, Consultant nurse – Stroke plus several regular volunteers. |
| Timing | Thursdays with assessments between 9.30 am and 10.30am or between 11.30am and 12 noon. Two separate exercise sessions held 10.30 -11.30, the other from 12 noon till 1pm. Participants have the choice as to which session to attend and can swap attendance time from week to week. Information session with all participants from both exercise sessions held from 11.30am – 12 noon. |

Figure 21: A typical journey through the ASPIRE programme



ASPIRE practice development data summary

Participants

Anyone who has been recently discharged from hospital, following admission for a stroke, or who is referred from the stroke clinic, with a new diagnosis of stroke or TIA, is eligible to attend. Not everyone is able to attend; as NHS transport is only provided for those who meet specific criteria; public transport very limited; and taxis expensive in this predominantly rural area. For those with no-one to drive them, this may delay their start till a month after stroke, or prevent them attending altogether, if they are not able to return to driving. There have been between 4 and 16 participants, in each of the two overlapping groups, at any one time, with an average of 10 members. Most participants are referred directly from the acute stroke unit, though some come through the stroke physician's clinic, community rehabilitation teams or occasionally through a GP. Some are referred via their GP and the TIA clinic, having had their stroke out of area, or never having been admitted, due to very subtle deficits.

Those attending the 'ASPIRE' programme to date, have had a wide range of risk factors, stroke severity and residual physical, cognitive and communication impairments; though, participants tend to be generally at the less disabled end of the spectrum, and many appear to have made a full physical recovery. Very few of those who have had a prolonged stay in the stroke rehabilitation units, (more than 6 weeks), are referred to the ASPIRE programme. Those with a prolonged inpatient stay, that have been referred, are usually the younger stroke survivors, who may not previously have met anyone else, aged less than 70 years, who has had a stroke. Most, though not all of those with significant residual physical impairments e.g. using a wheelchair for mobility, have at least been able to stand with assistance. All of those referred are living in their own home, including sheltered housing and extra care housing; none referred are living in residential or nursing home accommodation. This population are not excluded by those running the ASPIRE programme, but are either excluded by the referrers who may not approach this group of stroke survivors, or by the stroke survivors themselves who may refuse referral. Many of those attending ASPIRE have had comorbidities including; dementia, diabetes, cancer, cardiac pathologies, renal

pathologies, musculoskeletal issues such as arthritis in hips, knees or back, previous hip or knee replacements, and mental health issues including anxiety and depression. In addition, there have been a handful of participants with learning difficulties.

Although most attend following their first stroke, some have attended for the first time after a second or subsequent stroke; previous strokes usually being prior to the development of the ASPIRE programme, or in another location. Some participants have also been receiving physical or communication rehabilitation, from community or outpatient services and three participants have attended the ASPIRE programme at the same time as also attending cardiac rehabilitation. Two people have attended twice, firstly as the carer and then unfortunately as a stroke survivor.

Over the first 6 years from the start of the programme in January 2007 up till January 2013 450 people have been referred to the ASPIRE programme, of whom 359 attended. Unfortunately four of those referred died before starting, two from a further stroke, and two from other causes. No record has been kept of those approached, who declined to be referred, due to the large number and locations of possible referrers; including general practitioners, stroke physician, community stroke coordinators, stroke rehabilitation teams and the acute inpatient stroke team. Over the six year period, approximately 1200 people were discharged alive from the acute trust following a stroke, so those referred to the ASPIRE programme, represent just over one third of those with stroke, over that time. The age and gender profile, of all those referred to the ASPIRE programme, whether they attended or not, and their reasons for non-attendance or non-completion, if recorded, are summarised in figure 22.

Over the 6 years that data were collected for the practice development project, 258 people; 57% of those referred, 72% of those who started; completed the ASPIRE programme, i.e. attended 12 or more sessions. This compares to less than 20% of patients who complete cardiac rehabilitation programmes (Arena et al, 2012, Suaya et al, 2007). Of those who completed the programme, 66 attended for one or more review appointments. The remaining 74 have stopped before completing

the programme, either through choice, as they felt they had made a good recovery, or due to a number of other reasons including; transport difficulties, return to work, or through their own or a close family member's ill health. The age range, of stroke survivors attending ASPIRE, has been 22 – 92 years of age, with most in their 60s or 70s ,and the majority (61%) have been male. As can be seen, the age of participants appears to have an impact, on whether a stroke survivor is likely to start the ASPIRE programme, as a far greater proportion, 93%, of those under 50 referred, start the programme (42 out of 45) compared with those over 80, (54 out of 82 i.e. 66%). Of the three under 50 who did not attend; one had suffered the death of his father after referral, one had no telephone and did not turn up to a postal appointment and one was possibly an inappropriate referral due to longstanding anxiety issues, and despite arranging for his community psychiatric nurse to accompany him, he did not attend. In contrast, in those over 80 who gave a reason, most were either not well enough, or had transport difficulties, which might be expected in this age group, who often have a smaller social support network and more comorbidities; there were also a number in this age group who felt they had made a good recovery, and did not need to attend. Those over 80 who did attend, were more likely to complete the programme (42 out of 49 i.e. 86%), than those under 50 (25 out of 39 i.e. 64%); mainly as those in the younger age group were returning to work, or after a single attendance decided that they had made a good enough recovery, had answers to any questions and did not need to attend.

Caregivers, are identified by the referrer or the stroke survivor themselves, and are invited to attend, as many of the sessions as they wish. Although the majority of caregivers have been female, since most of the stroke survivors were male, male caregivers have also felt welcome. A total of 112 live-in caregivers (spouses or partners), attended regularly with the stroke survivors as a couple, four stroke survivors have been accompanied regularly by their daughters, one by his son, and two young stroke survivors have attended with their mothers. A number of other relatives including cousins, nieces, mothers, sons and grandchildren have attended for at least one session; usually the first session, during school holidays or when work commitments have allowed. During the exercise session, caregivers take the opportunity to either; take a break; or stay to encourage their partners; talk to

other caregivers or stroke survivors; or seek information, advice and support from the healthcare team. Many caregivers also take part in the information sessions, though some arrive for a chat at the end of the session, or make contact between sessions. This contact may be an email or phone call, asking advice about something their GP has told them, or something that they have read in the newspaper, or they may need support or advice about the person they care for, and wish to talk in private. This often occurs when the stroke survivor is low in mood, has changed in personality, or has cognitive impairment.

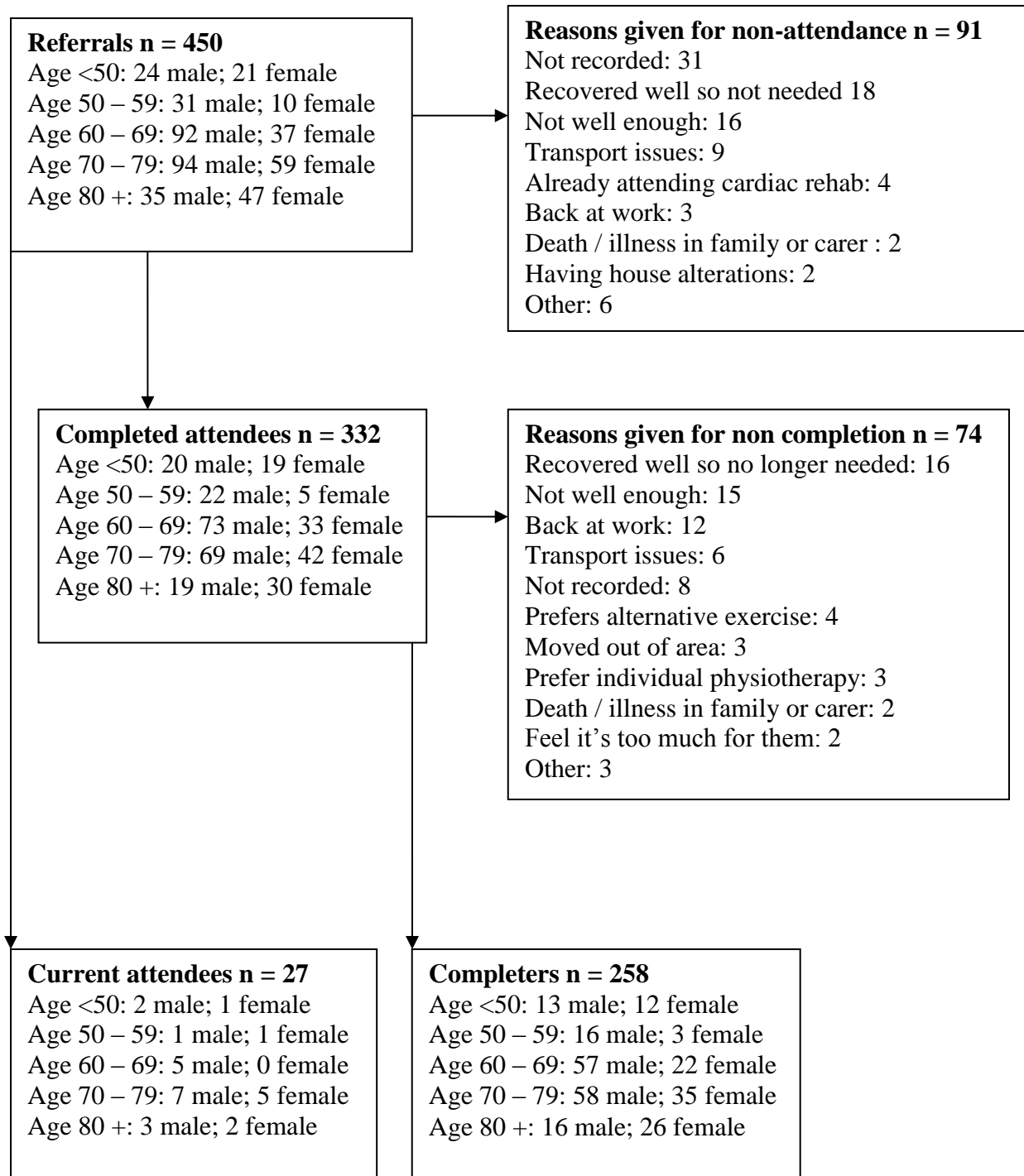
Adverse incidents

There have been very few adverse incidents during the ASPIRE sessions themselves; one person fell and cut their arm; another person fell though sustained no injury; two people have had a first post-stroke seizure which were recognised, managed and thereafter treated with medication; one person had a panic attack; and one long term diabetic became hypoglycaemic, which his wife recognised and dealt with instantly. In addition, one participant with a resolving right sided weakness, who arrived at ASPIRE with a new left sided weakness, which had developed that morning, was promptly admitted through the emergency department; and another participant who arrived having a severe nosebleed, that had already lasted over an hour, was taken to and managed by the emergency department. A further patient, who lost consciousness during an ASPIRE exercise session, due to a previously undiagnosed cardiac arrhythmia, was revived through appropriate emergency management, was admitted, and went on to have a pacemaker fitted, though unfortunately passed away a few weeks later. Four other individuals have died prior to completing the ASPIRE programme; one due to cancer, one due to a myocardial infarction, one due to a ruptured aneurysm and one due to infective endocarditis.

Three individuals have returned to the ASPIRE programme having had a recurrent stroke; one part way through and the other two shortly after completing the 12 weeks programme. Three other individuals have returned to the ASPIRE programme after a gap of two to three years, having suffered a recurrent stroke; one unfortunate individual had suffered an infarct and then a more disabling haemorrhagic stroke. Two of the three went on to repeat the entire programme, the

other individual, who had continued to exercise after his first stroke, came just to the first session, when he was referred on to an occupational therapist, in relation to residual cognitive deficits.

Figure 22 Referral and completion rates



Review, signposting and referral on

Progress towards goals is reviewed informally with participants, on each attendance, and formally at least once during the 12 week programme, usually at around the half-way point. During attendance at ASPIRE, a number of unresolved or new problems are identified and addressed, many of which require appropriate onward referral to other services, such as occupational therapy for cognitive rehabilitation or neurophysiotherapy for functional electrical stimulation. Some participants also reach a stage in their rehabilitation, where services such as support to return to driving or work are now needed. Usually, on about the tenth week, a participant is asked whether they have any plans, for how they will spend their Thursday mornings, after they finish ASPIRE, and the participants' plans for sustaining lifestyle change are also discussed. Their response then guides the rest of the discussion, which may include referring on to further formal rehabilitation input, or signposting to other services to provide ongoing support after completion of ASPIRE, including exercise on prescription, stroke clubs and active living centres. Many of the younger participants, are encouraged to join the local working age support group for stroke, set up by a previous ASPIRE participant. This process is enabled, as the treasurer for the club, is one of the regular ASPIRE volunteers. Participants move on from ASPIRE, usually once they have completed 12 sessions, although there is some flexibility, dependent on circumstances and choice. Occasionally, agreement is reached for a person to attend a specified number of additional sessions; most commonly for someone whose ASPIRE attendance has been disrupted, either by illness, or other factors such as bereavement. Table 48 summarises some of the key services, onto which the 258 completed ASPIRE participants, were signposted or referred.

All participants are offered, either an open or planned, follow-up review appointment, usually a few weeks after finishing the ASPIRE programme, though this is down to individual choice, and at least one person, requested a review appointment in 6 months. About half of participants take up the option of a review, with a small number negotiating a further or later follow up appointment; usually to support them in 'keeping on track'. All those completing ASPIRE, are referred, via a copy of their ASPIRE summary letter, to their local stroke coordinator. All participants are told, they are welcome to call in, if they are ever

passing on a Thursday morning. This also helps to reduce any concerns about ‘being abandoned’ (Stroke Association 2006; 2012), when a person finishes the ASPIRE programme. A number of past participants have made further contact either by phone, email or in person, when new issues arise, or with specific queries. Others have just turned up, sometimes months or years later to say hello.

Table 48 Signposting and referral on

| Signposting / referral on | Number of participants | % of participants |
|--|------------------------|-------------------|
| Stroke coordinator | 258 | 100 |
| Exercise on prescription | 72 | 28 |
| Stroke clubs | 17 | 7 |
| Outpatient neurophysiotherapy | 15 | 6 |
| Finance & benefits advice | 12 | 5 |
| Stroke Association family & carer support worker | 11 | 4 |
| Driving assessment | 5 | 2 |
| Outpatient OT | 5 | 2 |
| Social work support | 4 | 2 |
| Continence specialist nurse | 4 | 2 |
| Dietitian | 3 | <2 |
| Ophthalmology | 2 | <1 |
| Speech & language therapy | 2 | <1 |
| Community Psychiatric Nurse | 2 | <1 |
| Smoking cessation | 2 | <1 |
| Disability Employment Advisor | 2 | <1 |
| Orthotics | 1 | <1 |
| Community rehabilitation | 1 | <1 |
| Active living centres | 1 | <1 |

The cost-benefits of running the ASPIRE programme, have not been calculated; however, over the course of a 12 week programme, an average of 20 stroke survivors plus 10 caregivers, each receive a total of 24 hours input. This input is provided by a total of; 36 hours of band 7 neurophysiotherapist, 36 hours of band 6 stroke specialist nurse, 24 hours band 2 rehabilitation assistant, 12 hours band 2 administration support, half an hour each of pharmacist, dietician, and stroke coordinator, one hour of occupational therapist and more than 100 hours of volunteer support.

In order to illustrate how the ASPIRE programme fits together, in an individually tailored way, three case vignettes are given below.

Mrs L, a 73 year old widow, initially had to be driven in by family members to attend ASPIRE, as she had lost confidence in her outdoor mobility; although prior to her stroke, she had regularly travelled by bus. She also identified that she was unsure of what she should be eating for health, and wanted to lose some weight. She was given advice and written information on healthy eating and exercise, as well as attending the group information sessions on these topics plus exercising each week at ASPIRE. As her memory was poor, she felt it would be helpful to have some more support, so Mrs L's GP was contacted, suggesting a referral to a dietician.

By the end of the 12 week programme, Mrs L had lost 4 kg in weight, 2 inches from her waist, was walking regularly and able to catch the bus to go shopping. She still remained frustrated at the incomplete, though improved, recovery of sensation and dexterity in her affected left hand. She had a programme of exercises and activities to continue to progress this, and was advised to contact her GP for referral to individual physiotherapy, if she felt that would be helpful in the future.

Mr D was an overweight, 70 year old man, with residual weakness in the left arm and leg, plus high level balance difficulties. At his first attendance, he identified that his rehabilitation goal was to return to driving, and also to return to mowing his half acre of lawn; his secondary prevention goal was to lose weight and lower his cholesterol level. As well as the generalised information sessions which included discussions around exercise, healthy eating and medication, he was also given relevant information leaflets. The nurse consultant prescribed an alternative statin when he started experiencing side effects. Having successfully passed the computerised hazard perception test, which reassured his wife and himself, he was advised on a graded return to driving. His initially overprotective wife was confident and knowledgeable enough, after a few weeks, to allow her husband to return to mowing the lawn, starting with the smaller front garden. The exercise

programme he undertook, is outlined in table 49. All exercises gradually built up in terms of duration and intensity as detailed.

By the time he completed the ASPIRE programme, Mr D had lost 3 kilogrammes in weight, tightened his trouser belt a notch, driven to visit relatives 50 miles away, reduced his cholesterol level from 7.2 to 5.4 and was regularly mowing the bigger back lawn, whilst allowing his wife to mow the front and trim the edges.

Table 49: Exercise programme for Mr D

| Exercise | Purpose |
|--|---|
| Treadmill at a steady to brisk walk (2 – 10 minutes) | Warm up, fat- burning, and balance. |
| Motomed exercise bike against light resistance (1 – 5), forwards and backwards (2 to 5 minutes in each direction) | Fat- burning, cardiovascular fitness, leg muscle endurance and balance. |
| Light weights (1- 3kg) for shoulder push ups and biceps curls (3 x 10 repetitions) | Fat- burning, arm muscle endurance |
| Trampette – marching on spot (1 – 5 minutes) | Fat- burning, cardiovascular fitness, leg muscle endurance and balance. |
| Rowing machine against resistance (1- 10) (2 – 10 minutes) | Cardiovascular fitness, arm & leg muscle endurance and balance. |
| Cross-trainer (1- 5 minutes) | Cardiovascular fitness, arm & leg muscle endurance and balance. |
| Balance / wobble board (1 – 5 minutes) | Balance & leg muscle endurance |
| Exercise bike (2 – 10 minutes) | Cool down and fat-burning. |

Mr B was a 63 year old retired teacher and keen walker, who suffered a devastating stroke leading to a lengthy hospital admission, and leaving him with marked expressive dysphasia and severe right sided weakness. He was referred to the ASPIRE programme, 7 months later after discharge from hospital. He was also receiving once-weekly support from a community physiotherapist and attending a local gym encouraged by his wife, a sports teacher who was working part time. Mr B was very determined to improve and was able to walk with a quad stick and significantly hemiplegic gait, distances of up to quarter of a mile. He had only gross movement proximally in his upper limb and no active movement distally, though was able to maintain a grip on some equipment using some

increased flexor tone. His only stroke risk factor was previously undiagnosed atrial fibrillation. He identified his secondary prevention goal as returning to walking regularly, initially aiming for 1 mile at a time and his rehabilitation goal was to be able to return to driving. His exercise programme is identified in table 50.

Table 50 Exercise programme for Mr B

| Exercise | Purpose |
|---|--|
| Motomed exercise bike against light resistance (1 – 5), forwards and backwards (5 to 10 minutes in each direction) | Warm up then cardiovascular fitness, leg muscle endurance and proximal arm muscle endurance through maintaining hold on handlebar. |
| Treadmill at a slow to steady walk (2 – 10 minutes). | Gait symmetry re-education, cardiovascular fitness, leg muscle endurance and proximal arm muscle endurance through maintaining hold on handle. |
| Bilateral pull downs using very light weight (1.25 – 3.75kg) within available range of movement. | Arm muscle strength, power and endurance. |
| Active assisted hamstring strengthening in prone within available range of movement. | Leg muscle strength, power and endurance. |
| Rowing machine against resistance (1-10) (2 – 10 minutes) | Cardiovascular fitness, balance, leg and arm muscle endurance. |
| Walking practice in parallel bars with minimal upper limb support and mirror. | Gait symmetry, cardiovascular fitness, balance, leg muscle endurance. Cool down. |

4.10 Discussion Phase 1 research

There are a number of strengths and limitations, to this first phase of the study including; the recruitment, the interview process, data analysis and the findings; which are discussed in turn. A number of key principles were used, in order to keep the research process as rigorous as possible, which are discussed in the relevant sections. This included; not carrying out a literature review specific to individuals' experiences after stroke, prior to the research, in order to avoid imposing any external viewpoints, on either the data collection, or analysis processes. In addition, a reflexive approach was taken throughout the research process, as discussed below and in the relevant sections.

Reflexivity

As a practitioner-researcher, the author had to manage three diverse and at times conflicting perspectives. From the practitioner perspective, the author felt that objective evidence was needed to enhance the effectiveness of the ASPIRE programme, and to inform commissioners to support the ongoing provision of the service. As a research student, on a doctoral programme, the author felt the need to produce valid and original research, for credibility and recognition, professionally and academically. From a humanist perspective, the author wanted to advocate for those vulnerable, disadvantaged and devastated, by the effects of a stroke. The author used a mixed methods study because; it allowed the convergence of different types of data, to produce a more in-depth study of the intervention; because it represented a compromise between the opposing quantitative and qualitative research paradigms; and also because it fitted with the author's pragmatic worldview (Johnson et al, 2007).

A major issue, from being both researcher and practitioner, was that of the balance of power in the relationship. As one of the health professionals involved in running the ASPIRE programme, the author had ongoing access to both the ASPIRE setting and its participants. Although Charmaz (2006, p110) recognises this as having important benefits, for both data collection and analysis, it could also potentially have negatively affected the interview process, due to perceived conflict of interest, between the roles of clinician and researcher. Participants, particularly the stroke survivors, may have felt a dependence on the practitioner who ran the ASPIRE programme; which they attended at a difficult time in their lives, at a vulnerable and critical phase post-stroke. They may have felt an obligation, not only to participate in the research, but also to say what they thought the practitioner-researcher wanted to hear. In addition, there was a risk that the analysis could have been strongly influenced by clinical experience, in addition to the data.

Recruitment – strengths & limitations

In terms of recruitment, despite being approached by letter, there was a high conversion rate from potential participant to interview, with 7 out of 8 caregivers, and 10 out of 16 stroke survivors responding positively. This relatively high

recruitment rate may have been because those approached felt obliged to participate, because they knew the author. It is unknown why some potential participants did not reply; however, three of the stroke survivors who did not reply had returned to work, whereas none of those interviewed had. It may also be that those that did not respond to the invitation to be interviewed, had negative things to say about the ASPIRE programme, that they did not feel able to tell the author, thus the findings may have a positive bias towards the ASPIRE programme.

Interview process – strengths & limitations

In order to increase the rigour of the interview process, an interview approach was taken that was able to follow the emerging themes, ongoing analysis and conceptualisation, so that each interview was influenced by preceding interviews. Taking a social constructivist approach meant that the author was co-creating data with the participants; on reflection this will have been influenced by the fact that not only was the author a clinician, but also a female, white middle class, professional. Most participants were interviewed in their own homes, making them more relaxed, and shifting the balance of power more towards them, as they were on their own territory.

Although the intention of the research question, was to identify the views of participants, regarding the impact of the ASPIRE programme; those that agreed to be interviewed, may have given an overly positive view of outcomes, as they were interviewed by an individual, with whom they may have felt an affinity. This was not thought to be a major issue, as this phase of the research was not seeking to ‘prove’ the benefits of the programme in an objective way; rather it was exploring what the impact of the programme was, in the view of those who had completed the programme, in order to identify outcome tools to be used in phase 2. By virtue of the fact that all interviewees had completed the programme, they were almost inevitably going to express favourable views. In addition, none of the participants were still receiving clinical care, from either the author or anyone else in the host NHS organisation, at the time of their interviews, some 3 to 13 months after completing ASPIRE, so may have been less likely to feel obliged to give only positive views.

The only way to overcome this positive bias, might have been to have a neutral outsider carry out the interviews; however, without a deep understanding of the context and experience of stroke and the ASPIRE programme, this would have led to completely different data being collected, as interview data is constructed by both interviewer and interviewee. (Kvale,1996). Even if a neutral outsider had carried out the interviews, there may still have been a bias in favour of the programme, as all those interviewed had chosen to complete the ASPIRE programme. Conscious of this potential for bias, the interviewees were encouraged to be completely honest. The author reflected on this during the analysis, and felt that the established relationship and rapport that she had with interviewees meant they were likely to be more honest with her, than they may have been with an outsider. She reassured interviewees that she was keen to receive open and honest feedback, so that the ASPIRE programme could become as useful as possible, to those who chose to attend. The author's impression was that participants were happy to answer all the questions openly and honestly, and that they did not feel awkward, embarrassed or pressurised by the questions. Some paused and appeared to reflect before answering in a considered way. This was the case even in response to the question, "**what impact do you think the ASPIRE programme had on you?**"; which may have been more awkward, as it was being asked by a provider of the programme. Some whose non-verbal reaction initially appeared to be of surprise, that the author needed to ask as she had been there too, checked that was what was being asked about, before answering.

In order to set their views on the impact of the ASPIRE programme into context, interviewees were also asked about their life before stroke, and the effects of stroke. It was considered important to find out about the person's life before stroke, to try and get an insight into their personality, and prior ambitions, values and challenges. This part of the interview also helped the interviewee relax, to become less self-conscious that the interview was being recorded, and to realise that the author was keen to hear their story, and that they could set the pace of their response. In respect of the stroke itself, it was considered important to get a view from the inside, as to what the effects of the stroke had been, as it is often the less visible aspects of stroke such as reduced divided attention, memory

difficulties, or changes in personality that can have the most impact on a person's everyday life. Also, the author was aware, that as a physiotherapist, she might make assumptions about the relative impact of various physical, cognitive and communication impairments, and impose those views unconsciously on the interviewee. Where information was given in the interview about stroke severity, home situation and length of stay in the acute stroke unit, these clinical details were checked in medical notes. This information helped to contextualise the interviewee's experience of stroke, as the participants' feelings about the stroke, in addition to their views on ASPIRE, were an important part of the interview. It was anticipated, that the data gathered in this aspect of the interviews was to set the tone for the rest of the interview, and set the context in which the stroke occurred, rather than to directly answer the research question. This data gained more significance in the reflexive review (chapter 5).

The interviews carried out for phase 1, included only those who had completed the ASPIRE programme, as it was felt this would give the most detailed information about the impact of the ASPIRE programme; however, restricting the pool of participants in this way, meant there was no information from phase 1, on why people chose not to complete the programme. In addition, with only one interview with a male carer, there was limited data to identify issues for caregivers such as gender (Larkin, 2007). The author had noted in her 'praclog', that male caregivers do benefit from participation, although they often appear to gain more support from male stroke survivors than female caregivers. A further limitation was that for a number of interviewees, there was a considerable time lag between attending ASPIRE, and being interviewed (up to 13 months), which may have resulted in recall bias.

Data analysis & findings – strengths and limitations

Although a qualitative methodology was most appropriate for the first part of this study, on reflection, the author's inexperience and naivety about the complexities of a grounded theory approach, led to incomplete saturation and a more limited analysis of the data, gathered in phase 1. As someone with no prior experience of conducting qualitative research, and in particular a grounded theory approach which can take some time to understand (Glaser, 2001), the author's initial

analysis of the data (Neal, 2009) was somewhat superficial. The author has frequently encountered a similar superficiality of analysis, by student or novice physiotherapists, when assessing patients. As with the author's first attempts at analysing data using a grounded theory perspective, novice clinicians have a tendency to see only the most obvious patterns and jump to conclusions. On reflection, the author should have done as she exhorts her inexperienced clinical colleagues to do; to keep exploring (like unpeeling the layers of an onion), and keep asking why, in order to generate a number of different hypotheses. Instead, the author was analysing the data from an unacknowledged, biased perspective, and to an extent, only saw what the author was looking for. With the benefit of hindsight, this demonstrates how absorbed the author was, by the development of ASPIRE, such that she was not truly able to hear the voices, and views of the participants, who she interviewed for phase 1 of the research. Presenting the themes, not just the transcripts back to the participants, for member checking would have enhanced the trustworthiness of the data analysis. Formal member checking was not carried out; however, informal discussions with previous participants supported the analysis. A more formal process of member checking would have ensured any assumptions the author made were challenged.

On reflection, this limited analysis was probably also due to the author's lack of training, experience and self-confidence, plus a rather blinkered intolerance of ambiguity, which Corbin (p92 in Chenitz & Swanson, 1986) suggests, tends to limit the depth and complexity of grounded theory, generated by a researcher. Indeed, there was a risk that the drive to identify existing validated assessment measures for phase 2 of the study may have closed the author's mind to anomalies in the data, which did not fit with the themes that had been identified. This meant that some themes were likely to have been under-explored, and should have been pursued further in additional interviews. Although the analysis and findings were discussed with the author's doctoral supervisor and nurse consultant colleague, using a second researcher in the process of the analysis, would have challenged the author's perspectives.

A number of the 'primary strategies', identified by Creswell (2009) were applied to increase quality and rigour, plus ensure credibility, trustworthiness and

authenticity. In terms of credibility, this included using negative examples wherever they occurred. Those who agreed to be interviewed in phase 1 were generally very positive; however, this may have been due a sense of indebtedness to the author. Other aspects to the research process, that aimed to increase trustworthiness and authenticity, were the use of a research diary – the doclog’ to provide an audit trail and thereby confirmability, plus also the use of ‘thick description’, detailed information about not only the participants in the process (see tables 29 and 30), but also about the context in relation to the interviews, which increases transferability. The author had prolonged involvement in the field, which enabled a detailed understanding of the ASPIRE programme, and thus able to give an in-depth narrative about the programme. This very ‘embeddedness’ could have led to inadvertent bias, whereby as both practitioner and researcher, the author might have unintentionally imposed on the findings, a view gained from participating in the programme, rather than through analysis and interpretation of the data. It appears this did not occur, as two key issues outlined below, and which the author was aware of; did not feature in the findings of this study.

Firstly, many of those attending the ASPIRE programme, have reported that fatigue limits their ability to make the progress they would like, in terms of rehabilitation, including return to work, and also in terms of their ability to increase their levels of physical activity, in order to reduce their risk of stroke. Flinn & Stube (2010) having conducted three focus groups with stroke survivors, also found that overwhelming fatigue was a debilitating factor, which limited return to everyday occupation, and roles such as a return to work, driving and reading. ASPIRE participants not involved in phase 1 of the research study; have described their fatigue in fairly dramatic terms, using phrases such as ‘hitting a brick wall’ or ‘like being hit by a train’. A recent systematic review also identified fatigue, as one of the most prevalent symptoms after stroke (Lerdal et al, 2009). It is surprising that fatigue did not arise as a significant finding during phase 1 of the study, and was therefore not considered during phase 2 of the study. On reflection, this may have been because of the way the interviews and analysis were carried out, which did not seek to explore specific difficulties experienced due to the stroke, other than those brought up by the interviewee, and instead focused on the

impact of the ASPIRE programme on participants. An alternative explanation could be recall bias, due to the length of time between attending the ASPIRE programme, and being interviewed (up to 13 months).

In addition, although it is known that those with mood disorders after stroke (such as anxiety and depression, which were assessed in phase 2), are more likely to experience fatigue; no systematic records were kept of participants' fatigue levels. Participants' attention was therefore not drawn to fatigue as an issue. As no data has been gathered, either as part of the practice development, or as part of the research study, it is unclear as to whether attending ASPIRE, has an impact on fatigue. Alternatively it may be that those with fatigue, do not gain as much from ASPIRE as other participants, so may not complete the programme, thus making them ineligible to have participated in phase 1, or they may have declined to participate in phase 1. This is significant, as there is some evidence to suggest that those with fatigue after stroke, expect less from exercise and have lower self-efficacy expectations (Shaughnessy et al, 2006), despite others with stroke, reporting positive benefit from exercise (Flinn & Stube, 2010).

Secondly, although ASPIRE participants report that attendance at the programme, has a positive effect on some aspects of secondary prevention, such as self-efficacy and knowledge of stroke, another key aspect of secondary prevention is medication adherence. Medication adherence is known to be often sub-optimal after a stroke (Adie & James, 2010, O'Carroll et al, 2011), and those in the 65-79 age group, with no pre-stroke disability, which describes the majority of ASPIRE participants; are less likely to persist with medication, than those over 80 and / or with previous disability (Lummis et al, 2008). As part of the overall self-management strategy, all ASPIRE participants have their medication monitored, and where needed, appropriately adjusted by the prescribing stroke nurse consultant, in order to increase effectiveness, reduce side effects, improve adherence and persistence. This is similar to the transition coaching model, shown to have a positive impact on medication persistence and adherence after stroke (Bushnell et al, 2014). None of the interviews had discussed medication, possibly as it was not specifically asked about, but also maybe as those interviewed had no

issues with their medication, as they knew what they were for, and had had them optimally adjusted. Further exploration of this issue is needed. Finally, although not a finding in phase 1, anecdotally attendance at ASPIRE enhances social participation; this may be due mainly to increased confidence (Ellis-Hill et al, 2009), though also may be due to a reduction in emotional distress (Cardol et al, 2002). The impact of ASPIRE on stroke survivors' participation in work, and social activities, therefore needs further exploration.

4.11 Discussion Phase 2 research

Having identified from phase 1, the key areas of impact that informed the search for relevant validated assessment tools, these tools were tried out on those attending ASPIRE in phase 2 in order to evaluate; a) whether those key areas of impact lead to outcomes; and b) whether standardised validated tools currently exist, identified through a search of the literature, that are able to assess those outcomes. At the start of this doctoral process, with an unacknowledged bias towards quantitative methodology, the author's assumption was that phase 2 of the research would provide objective data, about the impact of the ASPIRE programme. In this section, the strengths and limitations of phase 2, in terms of recruitment and retention, and in terms of findings, analysis and the assessment tools used, are discussed.

Recruitment and retention

In terms of recruitment, a key factor that may have limited recruitment, was that participation was sought, prior to attending the ASPIRE programme, early after stroke. At this stage, many individuals are struggling to cope with the impact of having had a stroke, and may not be keen to add to that difficulty, by volunteering to participate in a study that involves completing a number of questionnaires. The burden for stroke survivors, of having to complete four separate questionnaires, may therefore have limited recruitment or retention for this phase of the study. In addition, all of the tools identified were written questionnaires, which may have limited the participation of those with cognitive or communication difficulties. One way of allowing some of those with cognitive and communication difficulties to participate, would have been to have the questions read out to them, and their response recorded for them. This would have allowed the use of gesture to support

understanding, and enhance communication for those with language processing, concentration and attention difficulties.

Furthermore, despite agreeing to the referral whilst still an inpatient, experience of contacting those referred to ASPIRE once they have returned home, in order to arrange their first attendance, shows that many are uncertain of whether to attend or not, or they may be unsure that they will attend the full programme. For some, their hesitation seems to be around the challenges of getting to a regular programme; for others, generally those who have made a good recovery from their stroke, they are uncertain of what the benefits of attending may be as up till this point their experience has been focused on recovery from stroke, rather than on secondary prevention. These factors are also likely to have limited recruitment to phase 2 of the study. Retention rates within phase 2, were in line with the proportions of people completing the ASPIRE programme. Overall, as discussed in section 4.7, it was predominantly logistical issues, around insufficient time between being referred and starting the programme, which limited recruitment to this phase; such that after over a year of recruitment, there were only 16 complete sets of data. The impact of this limited recruitment, and resultant small sample size, was that those who participated in phase 2, were a highly selective group, which may have affected the findings of this phase.

Findings, analysis & assessment tools used

The challenges in finding appropriate outcome tools, to evaluate a stroke self-management intervention, such as the ASPIRE programme, have recently been highlighted in a systematic review (Boger et al, 2012) which recognised; (i) the complexity of factors that self-management programmes address; (ii) the lack of an outcome tool that specifically addresses self-management of stroke; and (iii) that validated outcome tools that assess function, mood and self-efficacy are used instead.

The effect of using standardised validated tools, to assess the impact of attending the ASPIRE programme, meant that there was a risk that the inherent variability between individuals, might not always be captured, as the standardised tools grouped people into broad categories. That grouping together might also have had

the effect of masking differing results, with differing sub-populations of stroke survivors. The converse was true however. All of the assessment tools were able to identify a range of individual scores and changes, despite many participants being initially near the ceiling of some of these tools. On reflection, it would have been interesting to explore why some individuals were outliers, in terms of much greater increases or decreases on the assessment tools, than most other participants.

Some of the positive findings from the interviews in phase 1 were supported by phase 2, in terms of statistically significant gains in knowledge assessed with the Stroke Knowledge Test, and mood as assessed with the Hospital Anxiety and Depression Scale. Despite positive findings in terms of attitudes to exercise in phase 1, these findings were not replicated in phase 2 when assessed with the Cerebrovascular Attitudes and Beliefs scale.

Stroke knowledge test

It is known that the Stroke Knowledge Test can demonstrate that stroke education, delivered via a brochure to at-risk (non-stroke) populations, produces an increase in knowledge about stroke, that is retained for a week (Sullivan & Katajamaki, 2009). In the current phase 2 research study, Stroke Knowledge has been shown to have increased after completion of the once weekly, 12 week ASPIRE programme in an at-risk, post-stroke population, and that increase in Stroke Knowledge was demonstrated, at a time point between one week and three months after attending the programme. Sit et al (2007) also found an increase in knowledge about stroke risk factors, following an 8 week programme of facilitated group information sessions, based on adult learning strategies. The knowledge of stroke scale used, was based on one used with Hong Kong Chinese in a telephone survey, so inappropriate for the present study (Cheung, 2001). Stroke knowledge was also reported to have increased, in the study by Byers et al (2010), who compared a group of stroke survivors who had received an enhanced education intervention, involving motivational interviewing, along with their caregiver; against a control group. The intervention group had an average correct score of just over 18 out of 20, compared with 14 out of 20 for the control group,

when completing a Stroke Knowledge Test one month later; the initial scores for the two groups were not stated however.

Although not a motivational interviewing intervention, the ASPIRE programme uses a motivational interviewing style of consultation, that also involves caregivers, plus a multi-faceted and interactive approach to information provision; individual and group verbal information being provided by professionals and peers, supplemented by written, audio and video materials. In contrast to the study by Byers et al (2010), which provided a single intervention session, in the ASPIRE programme, there is also the opportunity to revisit topic areas, and ask questions at each of the 12 once weekly sessions, plus ad hoc, in response to telephone queries between sessions.

Stroke self-efficacy scale

In a similar way to this study, all ten participants in the study by Jones et al (2008) increased their Stroke Self-efficacy scores, by a small amount following a 14 week workbook based intervention; however, these participants had much lower pre-intervention scores (mean of 83.5), compared with 106.375 in the ASPIRE phase 2 study. In both studies, as scores were compared, pre and post intervention, as opposed to against a control group, it could be argued that some of the changes in stroke self-efficacy scores may be related to increased time since stroke, rather than due to the interventions. Increased time since stroke is likely to give increased insight and ability to reflect on performance, and thus make accurate judgements about task capability. This is likely to lead to successful achievement of appropriate tasks (“Mastery”), which it has been argued boosts self-efficacy (Bandura, 1997). It is unclear whether the lack of insight in those with cognitive difficulties, noted by the author in the routine use of the stroke self-efficacy scale, may have been a contributory factor to lower final scores, in some participants, in phase 2 of the research, since research participants’ cognitive abilities or insight, in relation to completing the questionnaire, were not recorded.

Carer strain

In hindsight, continuing recruitment, in order to get more data, would have been beneficial. Also interviewing phase 2 caregivers, in addition to completion of the

Caregiver Strain Index, would have allowed greater insight into the ability of this tool, to assess the outcomes from ASPIRE. The apparent reduction in carer strain, may have been due to a Hawthorne effect, or may have been due to the increased time since stroke. Harrington et al (2010) found a reduction in carer strain over time, in the control group as well as the intervention group, who had attended an exercise and education programme, similar to ASPIRE.

With such small numbers participating in phase 2, it was difficult to identify whether the lack of a clear trend, with some of the other assessment tools was due to; (i) the small numbers i.e. the study was insufficiently powered to detect a statistical difference; (ii) the type of statistical tests used i.e. non-parametric tests (iii) the poor fit of the outcome tools to the participants; (iv) the variable length of time after stroke for participants; (v) phase 1 and phase 2 using two different cohorts of heterogeneous participants or (vi) other reasons. Further studies in larger study populations, might help to clarify whether or not there were trends that were masked, by the disproportionate effect of individuals' scores, with such a small sample size. Larger scale studies would also be needed, to identify any trends in caregiver burden, and whether that could be assessed using the Caregiver Strain Index.

Furthermore, although the phase 2 research participants broadly reflected the usual ASPIRE population, in terms of gender balance, physical impairments and age, none of the participants were aged over 80, so the use of the assessment tools in this age group could not be evaluated. In retrospect, additional valuable information about the impact of the ASPIRE programme on individuals, plus the ability of the identified tools to capture that impact, would have been gained by interviewing all those participating in phase 2, in addition to using the validated tools. This would have given greater depth of information about the cohort participating in phase 1, and enable a comparison between interview findings and the validated tools used.

4.12 Comparison of the ASPIRE programme with other multifactorial programmes after stroke

The ASPIRE programme, is one of a number of different multifactorial programmes after stroke investigated, that aims to support self-management and secondary prevention; however, it is the only one to date, that has included those with residual impairment, at an early stage post-stroke, and so also focuses on rehabilitation.

Some of the key benefits of the ASPIRE programme, are similar to those identified by participants who had attended a community-based exercise and education scheme, albeit at a much later stage, 15-40 months after stroke (Harrington et al, 2010); i.e. gains in confidence, knowledge acquisition and a positive attitude towards exercise. This similarity is likely to be because of the similarity of the key components of the programme; exercise, goal setting, peer support and acquisition of knowledge. The key differences from ASPIRE, is that this scheme was set up as a cohort group, rather than rolling recruitment, and caregivers were not involved. This recruitment strategy allowed for group bonding, in a much shorter timescale, which may have been more appropriate at this later stage in their stroke journey, when participants may have more similarities. In the early stages after stroke, having a peer group just a few weeks ahead in their stroke journey, seems to help build a sense of potential progress and manage expectations.

Those interviewed by Harrington et al (2010), had already established their post-stroke identity, prior to attending the programme, and reported issues with loss of confidence, and loss of role; leading to an overall lack of purpose, which attendance at the exercise and education programme, helped them to overcome. In contrast, those ASPIRE participants who were interviewed in phase 1 of this study, who had experienced similar issues, viewed them as an integral part of the early phase of their stroke journey, which they expected to overcome. This suggests that the provision of an exercise and education programme, may be best provided in the early phase after stroke, as with ASPIRE. There were a smaller group of participants, not necessarily the most severely impaired, who despite

participating in ASPIRE, had still not fully created a positive sense of self' (Ellis-Hill & Horn, 2000) post stroke, who may have benefited from attendance at a further exercise and education programme, at a later stage post stroke as well.

Other programmes have, like ASPIRE, found the inclusion of caregivers in education and physical activity programmes after stroke beneficial (Marsden et al, 2010; Huijbregts et al, 2008; 2009); though these were both at a later stage post-stroke. The optimum provision, to support self-management in stroke survivors and caregivers is still uncertain, though is likely to be stroke specific rather than generic (Kendall et al, 2007; Cadilhac et al, 2011). The ASPIRE programme, in line with the review by Pearce et al (2015), provides; psychological, emotional and self-management support; addresses the variable information needs; and includes goal-setting, action planning and social support.

Protocols for a number of studies, of different multi-factorial programmes to support self-management, have also been published; however, none of these studies include those with residual impairments, at an early stage after stroke. As identified from the interviews in phase 1, a group programme is not for everyone. For those who dislike group situations, or who are unable to access a group programme due to transport issues; self-management support can be provided in different ways, such as workbooks (Jones, 2008; Joice et al, 2012) and web-based approaches (Puijk-Hekman et al, 2017). These type of approaches could also be complementary to a face to face group programme, such as ASPIRE.

4.13 Conclusions

The aim of this two phase research project, was to identify participants' views, as to the impact of attending the ASPIRE programme; then to identify whether those key areas of impact lead to outcomes, that could be assessed, using currently existing standardised validated tools. The evaluation was aligned with the inclusive and pragmatic nature of the ASPIRE programme. On reflection, this approach was responsible for some of the strengths, and also some of the shortcomings of the study, particularly the small numbers and selective nature of the participants, in both phases of the study. It is recognised that these research

results may be biased, as all of those who participated in the interviews in phase 1 attended and completed the ASPIRE programme, and all but one of the complete sets of data in phase 2, were also from a (different) group of participants, who had attended and completed the ASPIRE programme, so may be favourably disposed towards the ASPIRE programme, and also subject to a Hawthorne effect. This research did not identify, whether those who choose not to attend, or complete the programme, or those who are unable to attend due to transport or other issues are equally, or less likely, to benefit from attending the ASPIRE programme. Overall, it allowed some analysis of how the ASPIRE programme would work, in ‘the real world’, though made it more challenging to draw robust conclusions, about the outcomes from the programme.

In contrast, to some other post-stroke programmes, that have been, or are currently being evaluated, the 12 week, once-weekly, rolling programme ‘ASPIRE’, is a well-established, post-stroke exercise, information and self-management support programme, that includes those with all types of stroke, and their family members / caregivers. Hundreds of stroke survivors and caregivers have provided positive verbal and written feedback, after participating in the ASPIRE programme; however, this has to be considered in context, as the feedback involved a sample who chose to attend, so cannot be generalised to the total post-stroke population. The ASPIRE programme has been evaluated by a small scale, mixed methods, research study consisting of two phases; phase 1: interviews, n = 16 stroke survivors, 8 caregivers (Neal, 2009) then phase 2: validated questionnaires n = 16 stroke survivors, 4 caregivers.

Analysis of the interviews in phase 1 captured key impacts, from attending the ASPIRE programme, from this cohort of participants, and were organised in the following three themes:

- (1) A life I like – the confidence to do the everyday activities important to a person after a stroke
- (2) Changing hearts and minds – the confidence, knowledge and health behaviour change to reduce vascular risk after stroke
- (3) In the same boat – the benefits of peer support for stroke survivors and caregivers

Phase 2 showed that most of the ASPIRE participants, had short term increases in knowledge about stroke, as shown by statistically significant increase in the Stroke Knowledge Test, and improvements in mood, shown to be statistically significant in HADS depression scale. Improvements in confidence, reported in phase 1 were not shown to be statistically significant in the Stroke Self-Efficacy Questionnaire, although the majority of individuals had increased scores. Benefits were also reported from the peer and carer support (3 out of 4 caregivers showed positive change on the Caregiver Strain Index). Despite phase 1 interviewees reporting positive health behaviour change, in terms of lifestyle risk factors, there was no statistically significant improvement in the Cerebrovascular Attitudes and Beliefs Rating Scale, though there was girth loss in two of those overweight and lower blood pressures in some of the phase 2 participants.

Overall, the five standardised validated outcome tools used, were able to register a change, to some degree, for most participants, who attended the ASPIRE programme, so appeared to be a reasonable 'fit' to the outcomes identified from interview; however, some measures appeared more sensitive to change than others, an effect that was confounded by the ceiling effect with some tools. The small numbers and heterogeneity of participants in this study, made it difficult to clearly identify some outcomes using these tools; however, there was a statistically significant improvement in stroke knowledge and mood after ASPIRE. It was hoped that the individually tailored approach of ASPIRE, would enable those with very different previous lifestyles and attitudes, to benefit from the programme. All those who have attended ASPIRE, and either provided feedback, or participated in the research, had recently had a stroke; however, it is not known whether there may have been unidentified differences in response to attending ASPIRE, between those with different subtypes of stroke, or those with different risk factors.

In summary, this study has demonstrated some positive short term outcomes, for research participants who have attended the ASPIRE programme; particularly stroke knowledge, health behaviour change, mood, confidence and peer support. Further studies are needed to understand more about impacts on fitness and cardiovascular risk. Further studies are also needed, to compare the outcomes

from the ASPIRE programme, to other models of post stroke provision. In order to do this effectively, new stroke-specific tools, that take account of the diversity and individuality of stroke survivors, need to be developed, researched and evaluated. It is likely that optimum provision will include a number of different models, to support the wide ranging needs, abilities and circumstances of those with stroke and their families.

Chapter 5: Moving forwards after stroke - a framework for practice.

Reflexive review

5.1 Introduction

Having completed both phases of the research project, I reflected on the implications of the findings of that research, for practice. Clearly the ASPIRE programme was viewed positively by participants, and improved a number of aspects of life after stroke, including knowledge and confidence. In order to be commissioned widely in the current economic climate, the outcomes would also need to be cost effective. To be cost effective, the costs of delivering an ASPIRE programme, would have to be counterbalanced by a reduction in healthcare costs. This could be achieved if, for instance, the outcomes from attending ASPIRE effected a reduction in readmissions to hospital, including those due to recurrent stroke and / or mortality. These reductions are theoretically possible, as it is hypothesised, that the type of changes in lifestyle factors, reported by ASPIRE participants, can produce reductions in recurrent stroke, additional to those produced through secondary prevention medication alone (Hackham & Spence, 2007). It is also known that mortality rates are lower in stroke survivors with better physical and social functioning (Engstad et al, 2003). To demonstrate that attendance at the ASPIRE programme could produce these results, would require a large scale, randomised, controlled trial with economic analysis.

Although this could be a potential future research project, it felt several steps removed from the current research, which assessed participants' outcomes in terms of confidence, knowledge and mood, rather than measuring changes in physiological and health status. I then realised that with reductions in stroke mortality, leading to increased numbers of stroke survivors, living with the impact of a stroke; improvements in confidence, knowledge and mood were important outcomes in themselves. Rather than trying to 'prove' that replica ASPIRE programmes should be rolled out widely, I should instead be trying to clarify, what it was about the processes within the ASPIRE programme itself, that produced the outcomes identified, and then use this analysis to develop a framework to guide practice. Although the programme is in line with the seven common core principles to support self-care (Skills for Health, 2007,) I was keen to identify the specific processes, within the ASPIRE programme, that brought

about the outcomes achieved. The aim of this chapter is to reflect on my learning, through listening to and working with stroke survivors and their caregivers, in order to develop an interpretive theoretical framework, to guide the implementation of these processes in clinical practice.

The reflections in this chapter draw on, and from, data collected for the research phases of this doctoral programme, plus evidence from field notes gathered in my practice development diary ‘praclog’, and my research diary ‘doclog’. The two logs, their purpose, structure and anticipated uses are described below.

My ‘**doclog**’ was a research diary, in which I kept chronological notes of research processes undertaken, reflections on encounters with research participants and a task list of jobs to be done. I anticipated that the reflections might be helpful when it came to writing the reflexive review. The research process notes I found helpful, to ensure consistency and objectivity of approach for the qualitative phase. I also anticipated they may be of help to me, if carrying out any similar research in the future.

My ‘**praclog**’ was a diary, in which I kept chronological notes of plans and ideas, on the practice development intervention (ASPIRE), and notes on conversations and feedback from stroke survivors and caregivers, at any stage of their stroke journey, whether they had attended ASPIRE or not. I also jotted down reflections, triggered by clinical encounters with stroke survivors and caregivers, colleagues, volunteers, students and visitors. Having something captured in writing, supported me to crystallise ideas, in the planning phase of each PDSA cycle. I also anticipated that the reflections might be helpful when it came to writing the reflexive review.

I felt I needed to revisit the data collected in phase 1, because since completing the collection and analysis of this data, weekly involvement in the ASPIRE programme, had given me greater insight into the impact of stroke and the ASPIRE programme on stroke survivors and caregivers. In my original analysis of phase 1, despite intending a constructivist grounded theory approach (Charmaz, 2006), in hindsight I felt that the analysis had remained rather positivist in nature

(Holloway & Wheeler, 2002), due to its focus on the impact and outcomes from attending the ASPIRE programme. In this reflection, I wanted to learn more about the processes involved in the ASPIRE programme. I realised that to understand the processes involved in the ASPIRE programme, I needed to consider the ASPIRE programme, within the context of each stroke survivors journey to become aware of the processes involved, throughout the whole stroke journey, from before the stroke onwards. Although the phase 1 analysis had focussed on the part of the interview that discussed the impact of the ASPIRE programme, I had also asked about the whole stroke journey.

On reflection, listening to and analysing what this group of people, affected by stroke said about their journeys, had strongly influenced me, such that in my subsequent practice, I had been using a 'life-thread model' approach to rehabilitation (Ellis-Hill et al, 2007). This group of people included the 10 stroke survivors and 7 caregivers interviewed in phase 1 (see chapter 4). I also used field notes from my 'doclog', which included reflections during both phases of research, and so also included reflections on the 19 stroke survivors and four caregivers from phase 2 (see chapter 4). Finally, I also used notes from my practice development log ('praclog'). This 'praclog' included reflections on telephone conversations, with those referred to ASPIRE who chose not to attend, or those who started ASPIRE, but then chose not to complete. It also included observation and face to face discussions; with current ASPIRE participants about specific issues identified during this reflection, so that I understood their views whilst still attending ASPIRE, rather than views in hindsight when interviewed many months later. It also included notes on conversations with past ASPIRE participants, attending for outpatient rehabilitation, or at a local stroke club, to get a longer term perspective.

As local lead investigator and physiotherapist for the 'AVERT' trial, I also came into contact with a number of individuals, very soon after their stroke, from arrival in the emergency department and through their acute inpatient stay. Although I only made a few field notes in my 'praclog', about conversations with both stroke survivors and caregivers at this early stage after stroke, the shock they were going through had a powerful impact on me. Reflecting on this strongly

influenced my practice. All the stroke survivors and carer reflected on in the ‘praclog’, are referred to by pseudonyms.

To ensure clarity, words from phase 1 interviewees used to illustrate my reflections are *italicised*, in double quotation marks and have line number references. Comments from my ‘doclog’ are in **bold** and those from my ‘praclog’, used to illustrate these reflections, are in underlined non-italicised script, as they are not direct quotes from research participants; instead they are paraphrased from field notes at the time.

In addition, I also reflected on my practice in general since starting this professional doctorate programme, and my experience of working with several hundred service users plus their caregivers; not only clinically, but also within the context of involvement, in a number of research studies and service development projects. In reflecting on the processes involved, I was keen to consider

1. How life was interrupted by the stroke
2. Processes which appeared to enable or inhibit ‘moving forward’ after stroke.
3. How the ASPIRE programme may have supported people to move forward.

5.2 Interruption after a stroke

Immediately after a stroke, in the first few days or weeks, people initially seemed to focus on their previous life and plans and went through a period of mourning what they had lost; for instance Bob who said (line 160) “*I was active, the next day, you’re old.*” This transition period of mourning and grieving for what had been lost, was often accompanied by a feeling of uncertainty (Rittman et al, 2004), and appeared to last for a variable period of time. Often it seemed to be easier for people to focus on the small, everyday things that had been disrupted, rather than focus on the major losses due to the stroke. An inpatient on the stroke unit ‘Julie’ who spoke to me, the day after a dense right sided stroke, illustrates this point. She was crying, and I assumed it was directly because of the stroke, which had left her with dysarthria and a dense hemiplegia; however, when I asked what was upsetting her, she told me; I wanted to watch the Chelsea match last

night; and was frustrated that being in hospital, had prevented her from continuing with her previous plans. Although she recognised that she was in hospital, and was able to state that this was because she had been told she had suffered a stroke, she appeared unaware of the overall impact, and did not acknowledge her impairments, even when unable to move her hemiplegic limbs.

This apparent lack of awareness, is in contrast to the findings of Eilertsen et al (2010), who describe an initial phase over the first two months post stroke, of focusing on bodily changes; and Ellis-Hill et al (2000), who found that not just initially, but also one year after stroke, most interviewees still considered their body to be untrustworthy, and a focus for attention. The much greater emphasis on awareness of body functioning, by the interviewees in these studies, may be due to the interviews being carried out at later time after stroke; whereas, the comments from Julie were made the very next morning, after the stroke occurred when she was still in a state of shock, denial and disbelief. In addition, a sense of disconnectedness with body may develop further in the first few days after stroke, where it has been found that limited opportunities exist to be physically active (Esmonde et al, 1997; Bernhardt et al, 2004). Many of those who have stroke, have no idea what to expect in terms of their onward journey, and often assume that as it has not been fatal, it is something they will make a full recovery from; expecting a cure from their time in hospital, making comparisons with something more commonly encountered, such as a broken leg or a heart attack. For many, it comes as a shock, that their recovery may be incomplete, that the doctors are unable to cure them, and that much of the responsibility for progress and recovery, may be down to their own efforts. The type of rehabilitation approach taken; therefore, needs to embrace a client centred approach, which supports this transition to a long term condition (Cott, 2004).

All stroke survivors, interviewed for phase one of the study, were inevitably looking back at their previous life, from a post-stroke perspective, which may or may not have reflected the views they may have held, before their stroke. The majority of stroke survivors interviewed several months after their stroke, acknowledged that their life had changed forever, and thus tended to frame their answers, to questions about what their life was like before the stroke, by either

contrasting it with their current situation, for instance Jeffrey (lines 5 & 7) who said; *“It was OK, I had some sort of balance on my feet. I could talk better. Appetite was not very good”*; or by stressing how normal and problem free their previous life was. Bob said (lines 4-5);

“Oh it was very active. I was working, I could do my job - it was a manual job I could still do it. I was just a normal 65 year old man. I had my hobbies, interests, carpentry. Fine. No problems at all.”

In nearly every case, people were able to recall accurate details about the date and circumstances of their stroke, even many years afterwards, indicating the huge significance of the event. This is in line with other studies, which have also found that a stroke disrupts an individual’s planned life, causing a profound shift in circumstances akin to being moved to a strange new world (Ellis-Hill et al, 2000; Lawrence, 2010; Peoples et al, 2011). Even for those who have made a full recovery from stroke, they tend to reflect on and reappraise their life, and feel permanently changed by the stroke (Lawrence, 2010).

In contrast to what might be presupposed by health care professionals, changes caused by stroke may not always be negative. For some individuals, life before the stroke had been increasingly difficult, and the period of enforced hiatus immediately after the stroke, provided an opportunity for reflection and relief. One example was ‘Keith’, for whom the stroke was almost a welcome break from an increasingly difficult situation, from which he could see no way out. At his first attendance at ASPIRE, he described having a stroke and the enforced interruption to his previous life, as the calm after the storm. A number of other stroke survivors have described the stroke, as the best thing that could have happened to them, as it has allowed them to take stock, change direction, and end up much happier with their life. For instance Sheila, who when asked to sum up how life was for her now, (9 months) after her stroke said (line 234); *“It’s better, which is really quite extraordinary”*. It was therefore important to consider each stroke survivor, in the context of their own life narrative, as suggested by Ellis-Hill & Horn (2000).

The impact on caregivers of stroke survivors, often appeared to be even more profound, than on the stroke survivors themselves, as they restructured their lives

to take on the caregiving role (Silva-Smith, 2007). It is known that low mood can be prevalent in caregivers, particularly caregivers of older stroke survivors or those with more severe deficits (Berg et al, 2005). A significant proportion of caregivers experience strain, particularly those with poor health themselves, or those who need to spend a lot of time with, or helping, the stroke survivor (Bugge et al, 1999). Often it was those caring for stroke survivors with cognitive or mood difficulties, who were finding it most difficult, as illustrated by this quote from Jenny (lines 152-6):

“What I got out of it yes, in that I didn’t have to be here 7 days and 7 nights without any respite and with a very, very grumpy old thing, who wouldn’t do anything I said, who would sink back into drinking too much and you know, so yes, huge help and value to me.”

Even for those not involved in any significant amount of caregiving, they report being haunted by their memories of the time of the stroke, and the first few days after, when often their loved one’s memory of that time is very sparse. This has a marked impact on the caregivers, who may be frightened to leave the stroke survivor alone, as they are worried that their loved one will have another stroke; or may be feeling guilty, that they were unable to do anything to stop their loved one having the stroke; or blame themselves for some pre-stroke incident, that they feel was to blame, for bringing on the stroke. Smith et al (2004) found that friction might develop between stroke survivor and caregiver, due to the stroke survivor’s low mood and perceived apathy; such tension has been frequently noted amongst those starting the ASPIRE programme. ‘Liz’, for instance, at the first ASPIRE session with her husband ‘Greg’, appeared to be almost exploding with exasperation when she said; He does NOTHING. Greg, in contrast, just smiled placidly and appeared unconcerned.

Whatever the circumstances leading up to the stroke, shortly afterwards, the process of moving forward after stroke began, for both stroke survivors and their caregivers. For some, this process began almost immediately, for others it took more time. ‘Moving forwards towards life after stroke’ was the key process, identified within this reflection, and considered many aspects of a person’s life after stroke. This is in line with the findings around the importance of continuity and momentum in recovery (Ellis-Hill et al, 2009; Satink et al, 2013). In contrast,

the majority of studies on life after stroke usually focus on intensity and content of rehabilitation input (e.g. Bode et al, 2004; Kwakkel et al, 2004; English & Hillier, 2011; Jorgensen et al, 2010); or medical management of risk factors (e.g. Fletcher et al, 2010).

Researchers in life after stroke studies, frequently assess outcomes in terms of functional gains (Ada et al, 2006; Donaldson et al, 2009; Rensink et al, 2009; Invernizzi et al, 2013); survival; or physiological status (Rimmer et al, 2009; Raine et al, 2009; Fletcher et al, 2010); rather than focusing on the journey after stroke. There are studies which focus on some of the factors, identified by ASPIRE participants, that impact on life after stroke; such as mood (e.g. Hackett et al, 2005; Fung et al, 2006), confidence (e.g. Reed et al, 2010; Jones et al, 2008) and behaviour change (Greenlund et al, 2002; Daviet et al, 2012; Small et al, 2013); but they tend to focus on individual interventions designed to address one specific factor alone. In contrast, the ASPIRE programme addresses a multiplicity of factors, through a complex, responsive and individualised intervention, that by its nature, is much more difficult to define.

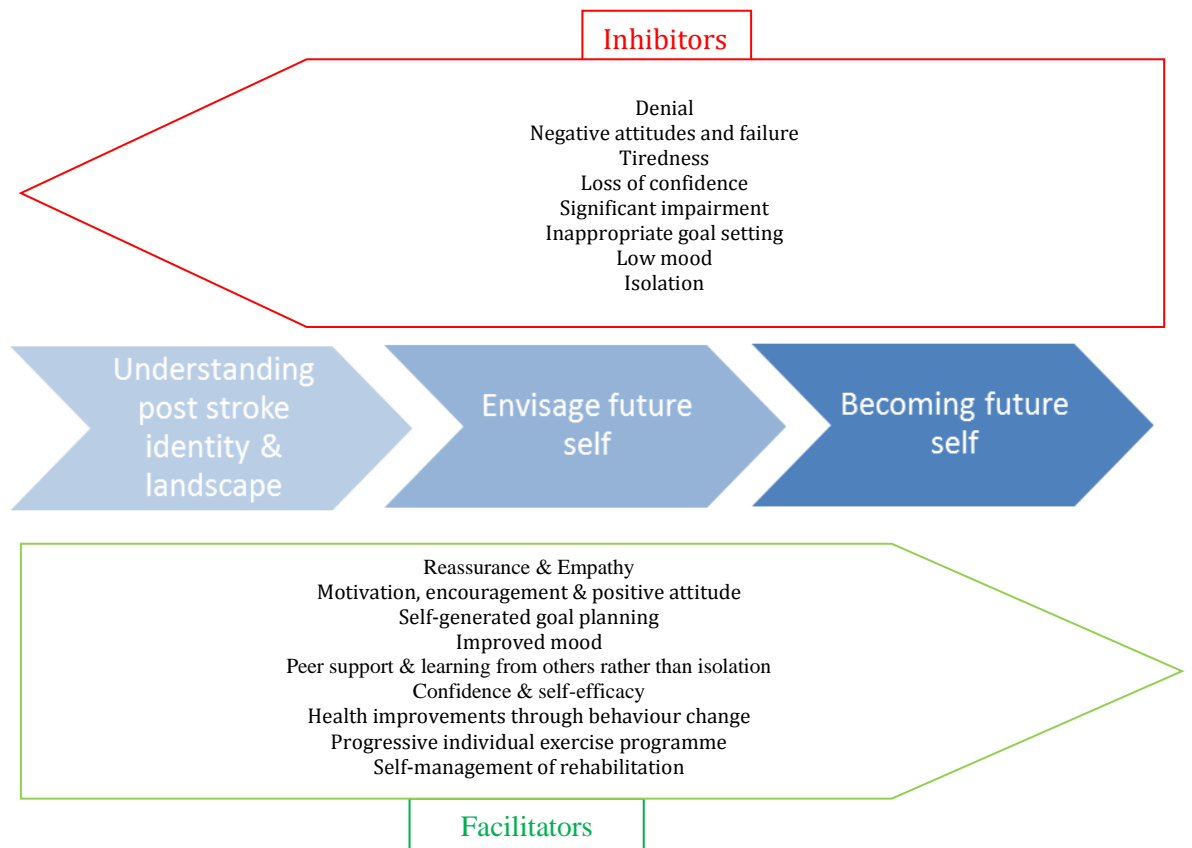
5.3 Moving forwards to life after stroke

Moving forwards to life after stroke could be compared to setting off on a journey, across an uncharted ocean, to an unknown destination, somewhere in the distance. On reflection, it seemed that for a person to move forwards to life after stroke involved three sequential key processes, for which there were a number of factors which acted as enablers or as inhibitors. Firstly, understanding the post-stroke landscape and their identity (see section 5.4); secondly, envisaging their future self (section 5.5); and finally, becoming their future self (section 5.6) i.e. establishing their post-stroke identity. These processes, and also the enablers and inhibitors to those processes, are illustrated in figure 23, and discussed in the phase in which they tended to be more evident, though could occur in all stages.

Although described and illustrated as a linear process, for the majority this journey was far from smooth; life often took on a far more turbulent course than previously, and people often moved back and forth between phases. Two examples from my ‘praclog’ illustrate this: ‘Cliff’ a previous ASPIRE participant

attending as an outpatient, described life after stroke as; like a roller-coaster. Another stroke survivor, ‘Karen’ who was attending as an outpatient, suffered a set-back in her progress, due to a burst blood vessel behind her eye, and referred to this event as having; come across another snake. She described her post-stroke life, as like a game of snakes and ladders, with progress being enabled by some things (the ladders), and hindered by others (the snakes). Factors such as denial, associated with the early stage post-stroke, could often recur at a much later stage, when a stroke survivor encountered a new and difficult situation, such as the cognitive challenges of returning to work.

Figure 23: Moving forwards to life after stroke



5.4 Moving forwards to life after stroke – understanding post-stroke identity and landscape

Firstly, each person needed to establish and recognise their identity, as someone who had had a stroke. Establishing an identity as a stroke survivor, involved understanding the irreversibility of having had a stroke, irrespective of the degree of recovery. As ‘Flora’, a stroke survivor at a regional stroke meeting explained; A stroke is for life.... This process of coming to terms with having had a stroke is not the same as acceptance. On reflection, two interrelated factors appeared to be involved in a person coming to terms with and understanding their post-stroke identity; the nature and degree of impairment, and the length of time since their stroke; though the relationship was neither predictably causal nor linear.

There are contrasting views on experiences of rehabilitation and recovery after stroke in the literature. Ellis-Hill et al (2009) found the vast majority of those interviewed following stroke, were hoping for recovery to normal. The participants in this study by Ellis-Hill et al (2009), were only interviewed once, shortly after discharge from hospital, and time since stroke is regarded by some as an important factor. Satink et al (2013) recently identified that after a stroke; people experience an ‘ongoing struggle’, between regaining their old self and roles, and developing a new identity; and suggested that self-management interventions after stroke, should enable adjustment and continuity where possible.

A systematic review of stroke survivors’ experiences of rehabilitation (Peoples et al, 2011), identified a number of key aspects in the rehabilitation process, under the theme of power and empowerment. These aspects included; providing relevant information, taking control through active participation in rehabilitation, individualisation and peer support; all of which are part of the ASPIRE programme. The importance of paternalism, and the right of a stroke survivor to choose not to decide or take responsibility, was also identified by Peoples et al (2011). This was not found in ASPIRE programme participants; however, as an optional component of the stroke rehabilitation pathway, this might be anticipated.

A longitudinal study by Eilertsen et al (2010), in which participants were interviewed on 12 – 14 occasions over 2 years, found a predictable and homogenous view of recovery after stroke. Eilertsen et al (2010) found a linear sequence of recovery, that moved from a focus on bodily changes, to activities of daily living, to understanding self, to going on with life; and defined a timescale for these phases. All six participants involved in the study by Eilertsen et al (2010), had a number of similarities; they were defined as having had a mild to moderate stroke, were women over the age of 65, who had an inpatient length of stay of at least an average of 24 days.

In contrast, Dixon et al (2007) found people either viewed rehabilitation predominantly as a recovery, or as an adaptation process, irrespective of the length of time since the stroke or other neurological injury. Those interviewed varied from 2 to 360 months since onset, so are likely to have experienced very different rehabilitation approaches. Participants in the ASPIRE phase 1 study, were interviewed only once, at a variable length of time since stroke, and had a diverse range of stroke impairments. The heterogeneity in findings may reflect each interviewee's stage in the process of moving forward after stroke, and be influenced by the extent of their residual deficits, and their experience of, and attitudes towards the rehabilitation and recovery process.

Sheila, who was interviewed one year after her stroke, by which time she had made an almost complete recovery, appeared to view the recovery process as something that just happened spontaneously (lines 47-54);

“I didn't speak for quite some while, I was given a pen and a pad and I tried to write things down but I couldn't really concentrate on what I was writing. Why I didn't speak I don't know. Whether it was because I thought I couldn't speak or the fact that if I spoke it would come out rubbish again, but, how long after it I don't know, (daughter) could tell you, but at some stage, somebody came in and spoke to me or said they were going to do something and I said thank you. And it wasn't that, it was a great relief to see that, to realise that I could speak and my speech came back quickly after that. And I now occasionally still stumble over a certain word but otherwise, fine.”

In contrast, Harry, interviewed 9 months after his stroke described how he had taken an active part in his recovery process as he explained (lines 207-14):

“y’know the balance on the wobble board that was quite interesting and that you know sort of makes you realise that you’ve got to, yeah that was quite a challenge. I sort of adapted it to learn to stand on one foot, well I thought this was helping me because I thought my degree of problem wasn’t that high, I could soon manage to stand but I thought well, you know, to make it trickier for myself and to see if I am improving I was sort of standing, attempting to stand on one foot and that sort of thing to help me.”

Leo, whose upper limb impairment meant that he was still unable to write, 9 months after his stroke, recognised the need for adaptation (lines 117 – 125);

“I do have a bit of trouble, because I play an awful lot of snooker. I can get my hand on the table but with this hand I can only get the 3 finger grip if you know what I mean? Because there’s 4 or 5, my forefinger and thumb doesn’t work at all. You see. And therefore I can’t get the screwback in the erm.... In the shots that I play. But I can play to a fashion, but not to the league standard that I used to be.”

Over the weeks attending ASPIRE, all participants’ attitudes tended to change; initially individuals tended to refer to themselves as stroke sufferers or victims. As time passed, and people moved forward after their stroke, they increasingly became more positive, describing themselves as stroke survivors rather than victims; or as ‘Alistair’, attending for an outpatient appointment 3 years after his stroke proclaimed; Not a stroke victim but a stroke victor! At this point after stroke, ‘Alistair’ had moved forward and established his new post stroke identity. A number of factors were identified, that could either inhibit or facilitate the process of moving forward after stroke. The initial part of the process of understanding their post stroke identity and landscape could be slowed down; particularly by a number of predominantly internal factors, including denial, negative attitudes, tiredness and loss of confidence.

Denial

Initially, a significant proportion of people seemed to find it very difficult, to acknowledge that they had had a stroke. They sometimes refused to discuss the diagnosis, as if by not giving it a name, the stroke would go away. This phase of denial was often found, and could take a widely variable length of time to move through, from only a few days to many months or longer. A common pattern for those still in denial, was for them to refer to the event as a TIA or a mini-stroke,

rather than acknowledging that they had had a stroke. ‘Gordon’ at his last ASPIRE session explained how he had felt;

At first I felt like a fraud coming here because I hadn’t really accepted I’d had a stroke. People told me but it went in one ear and out the other. You get it eventually. Coming here helps – talking to other people and also people like you who know about strokes. Now I know why I’m here.

Others, despite having marked impairment from their stroke, appeared to be in complete denial and simply, and often quite vocally, disputed the diagnosis initially. A key aspect to the ASPIRE programme, was supporting individuals to recognise and accept that they had had a stroke, in order that they could move towards managing their impairments, and start to implement secondary prevention strategies.

As the majority of participants started the ASPIRE programme within a short time of discharge after their stroke, many were still in shock and denial. During these initial phases, however long they took, most stroke survivors seemed to find it difficult to recalibrate their future plans, making it hard to move forward. As might be expected, those with less impairment usually seemed to establish their post-stroke identity more rapidly, than those with greater impairment. Those starting ASPIRE with significant impairment, generally seemed to have not yet understood their post stroke identity and landscape; this may have been partly as far greater adjustment was required, partly as the situation was still constantly changing as recovery took place, and partly as there was a reliance on others, usually health professionals, to give guidance.

Some ASPIRE participants reported experiencing conflict with health professionals, who tended to focus on their own perspective and contribution to the stroke journey, whereas the priorities for those with stroke and their families, were aspects such as returning home, to work and previous roles. At the ASPIRE programme, the author and her colleagues provided consistent and honest communication, which enabled stroke survivors to understand their position as a stroke survivor, with all that implied in terms of current and future impairments and restrictions, to abilities and participation. To do this effectively was often challenging, particularly when someone’s stroke had left them with significant

impairment, and had a devastating impact on their life, as it can be very difficult to predict levels of recovery.

One example was Steve, who was admitted after a traffic collision and was found to have suffered new and old strokes in his occipital and frontal lobes. He denied having any difficulties, and was determined to continue driving, despite visual field loss. He also had unacknowledged difficulties with memory, planning and dyscalculia. On discussion with his wife, some of these had been present for a while, and contributed to difficulties with their relationship. These cognitive deficits, also made it very difficult for him to continue living in, and restoring, a semi-derelect, isolated, rural property, and had forced him to return to living with his estranged wife. His initial focus on starting ASPIRE, was the need to prove that ‘they’ were wrong about his sight, and that he should be allowed to return to driving, so that he could transport the materials he needed, to continue his house renovation. Many lengthy, delicate and supportive conversations took place with both himself and his wife, over the course of his attendance, by the end of which he had acknowledged that he had suffered strokes, and also reluctantly accepted that a return to driving was unlikely. His wife reported that she was also better able to cope with living with him.

Negative attitudes and failure

Many stroke survivors were exposed to negative attitudes from friends and family, work colleagues and society as a whole. Some were even battling with their own negative attitudes towards stroke, due to their own past experiences, for instance ‘Phil’ who referred to a stroke as; a death sentence or ‘Pete’ who described himself as; worthless. This is consistent with the findings of Ellis-Hill & Horn (2000), in a questionnaire based study of first time stroke survivors, conducted up to two years post-stroke. In comparison to matched volunteers, the stroke survivors were more likely to have a negative view of themselves, be anxious or depressed and to be less socially active. These negative attitudes sometimes developed later after stroke, in those whose journey forward after their stroke was far from smooth, or who experienced failure; for instance Matt who developed a knee problem, as he explained (lines 265 -9);

“in terms of exercise I’ve had a problem with my knee for 4 months and it’s not that... it’s easy to look for a reason why you can’t continue to do exercise but in reality it’s been genuinely frustrating for me, I can’t just step out walking briskly without my knee being sore the next day and if I carry on it’s a bit more sore and I haven’t really found a way to resolve that.”

Others had experienced negative attitudes from health professionals, for instance ‘Lynne’ who despite weak active movement in all upper limb muscle groups, had been given a collar and cuff, and told by a community rehabilitation team to ‘forget about her arm’. ‘Lynne’ was low in mood, appeared to lack motivation and had changed from being a very active member of a number of social groups, to being virtually housebound. During the subsequent few months whilst attending the ASPIRE programme, we focused not only on physical improvements, but also encouraged her to build her confidence in social situations, such as speaking in a group setting during the information sessions, or being introduced to a newer ASPIRE participant to help reassure them. Over this time, she began to develop the ability to use her hemiplegic arm in functional activities, and also started to return to previous social activities, despite still limited mobility. The importance of these changes is underlined by Engstad et al (2003), who found a decreased risk of death in those who have better physical and social functioning.

Another example was ‘Adam’, who was still in full time employment in a demanding management role, with four years left before retirement, when he had a severe stroke that left him with a dense hemiplegia. When referred to the ASPIRE programme, 4 months after his stroke, he was mobile with a stick and ankle-foot orthosis with a stereotypical hemiplegic gait pattern; he had a stiff painful right arm with limited gross flexor movement at the shoulder and elbow; and was low in mood. Alongside the ASPIRE programme, he was still receiving individual physiotherapy and occupational therapy from a community based early supported discharge rehabilitation team. After several weeks, during which time he worked incredibly hard, in every ASPIRE session, on his exercise programme, both his walking pattern and amount of movement in his arm were improving. ‘Adam’ was beginning to understand his post-stroke identity and beginning to envisage his future self. He then arrived one week in tears, and informed us;

Now that it is 6 months since my stroke they don't think I will make any more progress. They told me I have plateaued so they (the community team) have discharged me.

It took time and a lot of reassurance to support 'Adam' to move forward again.

It has been suggested, that a number of factors influence rehabilitation potential; including therapist values, service limitations, type and intensity of rehabilitation input; in addition to the stroke survivors motivations, actions and physical potential (Demain et al, 2006). The example of 'Adam' illustrates how vitally important it was, that predictions about future abilities were based not only on the current evidence base, and the clinician's experience, but gave a range of potential outcomes, and supported the stroke survivor to achieve them, in order to move forward after stroke. How much better would 'Adam's' experience have been, if he had been told that usually most of the fastest recovery after stroke happens in the first few months, and that although it was likely that the rate of progress would now slow, there were things he could continue to work on and practice, that would support his improvement, though were unlikely at this stage to lead to a full recovery. A discussion could then have taken place about what were his primary areas to focus on, an action plan developed to work on those areas, and a joint decision reached as to whether the rehabilitation team were needed to support that plan.

Those with limited experience in stroke, would need to focus mainly on the evidence base for this type of discussion; whereas, those with more 'patient miles' will be able to draw on their experience as well, to give examples of how others in a similar situation had dealt with it, so providing opportunities for vicarious experience, which is known to build confidence (Robinson-Smith & Pizzi, 2003). 'Adam' has gone on to have stroke specialist rehabilitation from another provider, and continues to make significant physical, functional, psychological and emotional progress.

The experiences of 'Lynne' and 'Adam' are not unusual, as previous research has shown that stroke survivors and health professionals, may have different goals and expectations, of outcomes from rehabilitation (Sabari et al, 2000; Wiles et al,

2004; Robison et al, 2009). This is particularly significant now that stroke is increasingly being recognised as a long term condition, which may require episodes of rehabilitation input over the stroke survivors' lifetime. This highlights the importance of those working with stroke survivors, not only having expertise and skill in managing stroke, but also a high level of inter-personal and communication skills, compassion, understanding and a positive but realistic attitude.

Tiredness

Although the findings from phase 1, which focused purely on the impact of attending the ASPIRE programme, did not identify fatigue, the impact of tiredness on the ability to move forward after stroke, was identified by four of the phase 1 interviewees, plus a number of other stroke survivors. Some such as Matt referred to the impact of tiredness on their physical abilities (lines 385-6, & 399 – 403);

“I think when I'm tired, I think when I'm tired my balance is worseBut this guy watching me last night said um – he asked if I was alright and I said yeah – sure and he said are you sure you're alright – you're worrying me staggering around like that. Well you know, I wasn't staggering around but I was obviously slightly, slightly unsteady and on Friday, at the end of, at the end of a fairly full week for me last week, I came home here and I stumbled in the kitchen a few times”.

In contrast, Jack from phase 2, commented on how tiredness impacted on him cognitively;

‘tiredness due to Christmas, holiday and other commitments, I had a job getting my head round things. Things are on the up now....’.

Bill talked in detail about how the tiredness and his mood interacted (lines 153 – 7 & 204 - 210);

“Yes you're tired and yes things make you exhausted you know, even 5,10 minutes doing something and you really feel tired. You get fumbly and you get, shall we say, your anger starts and then you start getting irritated. That is the problem you know what it is going to be good for you to do, exercise, projects, working with the hands, writing whatever, but there seems to be something in the medication that makes you feel achey and tired The trouble is I do find that, within a few minutes, and this is the thing, it's not an exaggeration, within a few minutes, sort of 5, 10, 15 minutes, I'm exhausted. And finding I'm wobbling, I'm losing my balance, breathing really hard, it's very frustrating. There's still an awful lot of frustration, of, you know, wanting to do things and not able to. Or, and of course the exhaustion brings on the anger, you know, one of those vicious

circles. So I don't want to start when I know I'm going to get tired and because I'm tired and I've only just started the job I'll get angry, you know?"

Fatigue has also been shown to be negatively correlated with stroke self-efficacy (Muina-Lopez & Guidon, 2013), although none of the interviewees with fatigue in phase 1 commented on this.

Often participants, particularly though not always, those with little other impairment, commented on the overwhelming and sudden nature of post-stroke fatigue, for instance 'Gordon' who described it; like being hit by a train or 'Karen' who have referred to it as; feeling as if the plug had just been pulled out. The 'unique characteristics', and often devastating impact of post-stroke fatigue on daily life, were also commented on in the study by Flinn & Stube (2010), who suggested that stroke survivors needed to know that fatigue was a genuine and well-recognised post-stroke symptom, in order to find strategies to deal with the fatigue, and move forward with their lives. Stroke survivors and their family members, who had heard and understood the oft-repeated rehabilitation message, about the need for practice and repetition to maximise recovery, needed to have fatigue 'legitimised' as a post-stroke symptom, to understand that the issue was not lack of motivation or laziness; as many caregivers believe that stroke survivors' need for sleep is excessive (Smith et al, 2004).

Many stroke survivors reported that they needed a regular daytime sleep, to help them to cope; for instance Jeffrey having already explained the impact of being tired on his speech, vision and mobility who said (line 221); *"I mean if you weren't here now I'd probably go to sleep."* Bob had also learned to pace himself as a strategy to manage his fatigue as illustrated by this quote (lines 52-3);

"Yes, so I could just relax and do a bit and when you feel tired, just rest and do a bit more. I think the first thing I did, I was in the garden."

Flinn & Stube (2010) identified a number of management strategies for post-stroke fatigue, such as use of adaptive strategies, and pacing, that were thought appropriate to be taught by an occupational therapist. These strategies were implemented as part of the ASPIRE programme, to support people with post-stroke fatigue, to move forward after their stroke, though were encouraged by

nursing, physiotherapy and volunteer staff, as no occupational therapist is involved with the programme on a weekly basis.

Loss of confidence

For most stroke survivors, a major issue after stroke limiting their ability to move forward, was not the attitudes of others, but their own internal loss of confidence, as Paul put it (lines 81 - 85);

“It’s a thing I’ve been, it’s been very hard to reconcile the fact that I’ve had it...You know. It takes your, it took my confidence away. But I’m getting that back, slowly.”

Loss of confidence and self-efficacy after stroke has been correlated to depression and lower quality of life (Robinson-Smith, 2002). Reed et al (2010) found that loss of confidence after stroke, was due to others attitudes to disability, and also due to concerns, about abilities to overcome physical difficulties in getting around. A further contributory factor to low self-efficacy is the lack of confidence in their body, and the fear of having another stroke (Ellis-Hill et al, 2000). In contrast, the importance of increasing confidence, has been identified in contributing to; positive outcomes from rehabilitation (Ellis-Hill et al, 2009); in enabling stroke survivors to create their new social identity (Reed et al, 2010); and in providing some protection against post-stroke depression (Lewin et al, 2013). There is increasing evidence that self-management interventions can increase self-efficacy, in those with stroke (Jones et al, 2009; Jones & Riazi, 2011). Confidence was built in the ASPIRE programme; through taking a self-management approach; through reassurance and encouragement from both the health professionals and stroke survivors; through providing vicarious experience; and through highlighting the progress already made.

5.5 Moving forwards to life after stroke - Envisaging future self

Once an individual had started to understand their post stroke identity and landscape, then a number of both internal and external factors could help to facilitate the next stage, in the process of moving forward after stroke; envisaging future self. In the ASPIRE programme, it appeared to be important to not only support a person with stroke to orientate themselves, to a new and unfamiliar landscape, but also to ‘paint’ some possible future landscapes, and to point out the

signposts to those possible futures, to enable those with stroke, their family and caregivers, to explore their new environment, and plan their own journey into the ‘not yet known’ rather than the unknown. This helped generate an air of expectation (Guidetti et al, 2009), and a sense of an alternative future, rather than the only possible option, being a return to the previous and familiar. The factors identified, that enabled this part of the process of moving forward after stroke, were reassurance and empathy; motivation, encouragement and a positive attitude; improved mood; appropriate goal planning rather than inappropriate goal setting; and peer support and learning from others, rather than isolation.

Reassurance and empathy

The first session was critical, in setting the tone, for the rest of the ASPIRE programme. The focus was on reassurance, and establishing where a person was, in terms of knowledge about stroke, and coming to terms with having had a stroke. Reassurance was also provided, by the presence of staff with specialist knowledge of stroke supporting stroke survivors and their family members to come to terms with and cope with the stroke, identified as a key role for nurses in stroke rehabilitation (Burton, 2000). Reassurance was also provided through monitoring participants’ health; the value of these ‘rudimentary checks’ was stressed by Paul (lines 237 – 45);

“At least you felt you were exercising, you were exercising in a controlled environment, you had the feeling well if anything did happen to meBecause there is this thing well, am I doing it too hard, going at it too quick sort of thing and err.. I know once I was told, you have your blood pressure taken when you get there and once my blood pressure was up and she said you’re not going on the treadmill today or something like that, because it might be a bit... we’ll see what your blood pressure comes down to after you’ve been round the rest of it, you know, and it was back down again, you know.”

The reassurance and empathetic support, from other ASPIRE group members, also appeared to help individuals cope with the psychological, social and emotional issues, inherent in living with stroke, through having shared experiences and understanding; thereby reducing isolation (Reed et al, 2010; Morris & Morris, 2012). Bill recognised this (lines 86 - 90);

“You know, I picked up few sort of, some person saying something clicked with me thinking that and just hearing different people’s reactions. It’s

talking to other people reinforces the fact that you're not alone, other people know how you feel and, and it's good to empathise. If you empathise with the person who's saying, saying the same things you feel, it gives you a better understanding of how you feel."

Dixon et al (2007), in a study involving people with stroke and other sudden onset neurological disability, also found that those participating in rehabilitation, benefited from external reassurance and support, from both health care professionals and others in a similar situation. Guidetti et al (2009) also found that stroke survivors, albeit at an earlier (inpatient) stage of rehabilitation, benefited from emotional support and reassurance, though in addition, initially required more practical, physical support. Understanding their own feelings, helped people understand their post-stroke identity and landscape, and enabled them to be ready to start envisaging their future self.

Motivation, encouragement and a positive attitude

Encouragement, and a positive attitude from staff and peers, motivated and supported stroke survivors to move forward after stroke, by helping them to envisage their future selves. This social motivation is recognised as a key element supporting self-efficacy (Bandura, 1997). Bob explained how the ASPIRE programme supported this process (lines 92 - 96);

"I think, it's given me the courage to carry on. It's given me the, how can you say, given me the....it makes you, it buoys you up. It buoys you up to say there is a future out there, you will get better and you will carry on and do the things...That's what the ASPIRE has done to me."

Others have also found participation in a group programme of exercise or relaxation after stroke can increase participants' confidence, and improve motivation for them to play an active part in their recovery (Carin-Levy et al, 2009).

In the ASPIRE programme, motivation and a positive attitude started right from the first session, with the discussion with professionals about hopes and expectations, which led to participants coming up with an individual plan. In order to do this, they needed to identify from within themselves a 'sense of purpose' (Reed et al, 2010). The plan identified might have been related to recovery from stroke, or reduction of recurrent stroke risk. By listening to the stroke survivor, the

intervention was personalised to fit within the individual's own life and circumstances, as suggested by Ellis-Hill et al, (2000). For many, though not all participants, this included planning goals, measuring progress towards and providing support in achieving those goals which helped provide motivation, as Harry explained (lines 272 -7);

“It spurred me on in that way, by seeing the, by measuring the improvement, you could get benefit from that. Yeah it generally gave me goals and it widened my horizons to getting me back to being fit. You know it was stressed, that you've had a knock, a blow, but we're here to help you and I know that I benefited from that.”

Self-generated goal planning rather than inappropriate 'client centred' goal setting

Not everyone was keen to set goals, depending on their previous experiences. Many professionals believe that patient centred goal setting provides motivation, improves team communication and achieves better outcomes (Siegert & Taylor, 2004); and there is some evidence that challenging, focused goals improve performance in the short term (Levack, 2006). Dixon et al (2007) found that neurologically disabled adults also viewed goal setting as an important process to help them plan a recovery path.

It is important to recognise when an individual is ready to set goals. Unfortunately for some stroke survivors, some health care professionals appeared to be so focused on goal setting, that they appeared not to recognise whether an individual was ready and able to play an active part in that process (Levack et al, 2011). Barnard et al (2010), in an analysis of goal setting meetings with neurologically impaired individuals, also found professionals tended to dominate, and often made significant modifications, during the process of translating patients' wishes into documented goals. This appeared to have happened with 'Pete', who was very low in mood when he started the ASPIRE programme and explained that; Goals always lead to disappointment. 'Pete' had previously been encouraged to set goals by his rehabilitation team, before he had understood the impact of his stroke and had wanted to set a goal for returning to skiing. At the time, he was unable to stand or transfer independently so the rehabilitation team had tried to dissuade

him from his goal. He had then become very low in mood and non-compliant in rehabilitation sessions.

Increasingly, those involved in rehabilitation are encouraging self-management, by changing their approach along the continuum from “benign dictator” to “reluctant democracy” (Norris & Kilbride, 2013). Despite this shift towards an emphasis on self-management, as yet there appears to be limited recognition of the importance of ‘self’. The focus in traditional stroke rehabilitation remains on involving and agreeing goals with the person with stroke and their caregivers in the rehabilitation process (Intercollegiate Stroke Working Party, 2012); rather than understanding and supporting the person with stroke to plan their own goals for their post-stroke life. Taking this life-thread approach (Ellis-Hill et al, 2007), enables the person with stroke to take back control of their own life, focused around their own perspective on self and identity. The positive atmosphere and culture of the ASPIRE programme, support a process of self-generated goal planning, by the person with stroke, that is supported by, rather than initiated by, the healthcare professionals.

For those not ready for planning goals in a formal way, an initial discussion and an optimistic atmosphere still set a positive tone for the future. Guidetti et al (2009) refer to this as ‘creating an air of expectation’, which supports participants to foster a positive attitude and generate their own appropriate goals at a stage when they are ready. As with a community exercise and education scheme run for those later after stroke (Reed et al, 2010), the ‘nurturing group environment’ in the ASPIRE programme supported individual’s progression. As Bob explained (lines 96 - 100);

“Not just in the exercise machine, they were incidental, but the major part of it was maybe to meet other and see how they recover and you think, well if they can recover, I can recover. And the physiotherapist down there gives you the relative (sic) exercises and giving you encouragement, and that’s been important to me. That’s what drove me on I think and that’s what helped me to recover.”

In the ASPIRE programme, self-generated goal planning involved moving away from the approach of goal setting, however ‘client centred’. Goal setting could be compared to asking someone where they want to go, out of the limited choices

available on a defective satellite navigation system, which will only take a person to places they have previously been. In contrast, successful achievement of appropriate self-generated goals appeared to improve self-esteem. To support a stroke survivor to generate appropriate goals, required the ASPIRE team to metaphorically show the stroke survivor a map of their current location, explain the key so that they could work out the features of the landscape, then allow them to choose their own direction of travel, and support them along the way. To do this empathetically required the ASPIRE team to understand the individuals own circumstances. This approach appeared to support the psychological, as well as physical rehabilitation, of stroke survivors (Eilertsen et al, 2010) and give them the skills to continue to generate and achieve, on-going appropriate goals after completion of the ASPIRE programme. An example is 'Kate' from phase 2 who after completing ASPIRE declared she; '**must practice her handwriting**', and had a goal of being able to catch a local bus, who has since sent postcards, from coach trips and holidays from all over England.

So with 'Pete', who had started ASPIRE with an unrequited goal of returning to skiing, at a stage when he was barely able to take a few steps with a quad stick; rather than trying to dash his hopes, the author worked with him to help him understand his new identity, and also identify what it was about skiing that was important to him. He was then able to recognise what was possible for him at this stage in his stroke journey, and was able to start identifying what he needed to do to achieve his 'aspirations', (he still refused to call them goals). Several weeks later, he announced that he would be absent from ASPIRE the following week, as he and his wife were going to Switzerland. He had come to the decision, that it was the fresh clean air and wonderful views that were more important to him, than the skiing. The ASPIRE team received a postcard announcing that they had got there safe and sound, he had managed to have a shower and to function and was walking more and thanked the team for making it possible.

In addition to mapping out a landscape, it also seemed to help to give stroke survivors a sense of timescale. For all stroke survivors, the journey to a life they like seems to be far longer than they ever anticipate. I found it helpful to use the word 'yet' in conversations. I also helped the stroke survivor set realistic

timescales for progress, by asking them to ‘guestimate’, based on the speed of progress so far since their stroke. I could only provide them with a limited amount of information about the journey ahead, based on what I knew about that individual stroke survivor. It was therefore vital to understand as much as possible about what was important to that individual, their values, beliefs, expectations and experiences. In the ASPIRE programme this was done through taking the time to explore these aspects at an individual’s initial session, using open questions such as ‘how have things been for you since you got home from hospital?’

Improved Mood

It is thought likely that interventions that improve self-esteem and perceived control can help individuals take control of their own future, and improve their mood. This is critical, as both low mood and anxiety are common after a stroke, with anxiety affecting up to a quarter of stroke survivors (de Wit et al, 2008) and low mood affecting up to half of stroke survivors (Hackett et al, 2005).

Heterogeneity in studies, in terms of time since stroke, definition of low mood and source of study populations, make estimates of prevalence variable (Bhogal et al, 2004). Low mood has been linked to lower quality of life (Jonsson et al, 2005), plus poorer functional outcomes and tends to be more common in women (Appelros et al, 2010).

Emotional distress is recognised as an important factor leading to limited social participation (Cardol et al, 2002). It has also been demonstrated that low self-esteem is correlated with depression (Fung et al, 2006), and that lower levels of perceived control are linked to low mood and anxiety, in the first few months after stroke (Morrison et al, 2005). This is important, as low mood and low self-esteem have been linked to restricted participation after stroke (Chau et al, 2009), and furthermore, decreased social and physical functioning are linked to a higher risk of death (Engstad et al, 2003). As detailed in chapter 4, anxiety and low mood were evident in a number of ASPIRE participants. Low mood was found initially particularly in those with functional difficulties, who either openly or subconsciously realised that a return to their previous life was not going to be possible; as Bob phrased it (line 84) “*Because it’s quite easy for me to be discouraged I suppose*”

Improved mood was evident in some of those who had attended the ASPIRE programme, as it supported them to not only envisage, but also become their future selves, as illustrated by the following quote from Mary (lines 101 - 106);

“I thought it was brilliant. It gave me confidence, a lot of confidence because at first I didn’t want ‘Daniel’ to go out - I mean he didn’t play golf for quite a few months afterwards. And I didn’t want him to go out anywhere without me because I was frightened of it happening again. Every time if you got a little twinge anywhere, that when am I going to have another one? But it just – it got me into exercise for one thing and it gave me so much confidence that gradually this fear just went and I’m fine.”

Carin-Levy et al (2009) also found their group programmes after stroke improved aspects of self-perceived quality of life, such as increased confidence and a sense of empowerment; irrespective of whether participants were in the exercise or the relaxation arm of the study. This implies that it is the presence of peers in the group that makes a difference to the stroke-survivors’ quality of life, rather than the exercise programme per se. It is possible, that supporting stroke survivors to develop the skills and strategies to reduce psychological stress, might be one of the processes occurring within the ASPIRE programme; as a recent review (Lawrence et al, 2013) found that mindfulness-based interventions i.e. structured group-based self-management programmes, appeared to reduce anxiety, depression, mental fatigue and blood pressure.

Peer support and learning from others rather than isolation

Providing opportunities for peer support helped the stroke survivor to move forward after stroke, by supporting them to envisage their future self. Having people, at different stages after their stroke, in the same group at the ASPIRE programme, enabled individuals to act as role models, or as ‘buddies’ sharing the journey together. In addition to the support provided by professionals, this support from peers was another source of social motivation recognised as increasing self-efficacy (Bandura, 1997). The importance of an ‘informal support network’ to provide both encouraging support, and an idea of future direction, was also recognised as an important component in supporting individuals to create new lives, even at a much later stage after stroke (Robison et al, 2009; Reed et al, 2010; Schouten et al, 2011). The opportunity to learn about their situation from

others, including staff and other stroke survivors appeared to be critical to moving on from this phase. It was not just factual knowledge about having had a stroke that was needed, but also the emotional side as stroke survivor Bill explained (lines 104 -111);

“It’s just that I think from an emotional point of view and reinforcing and confirming where you are the chatting with other stroke, not victims....SurvivorsYou know it helped on an emotional level to pick you up, make you feel right, you know. Where you were doubting what you were feeling, having it confirmed by somebody else sort of reinforced it a bit for you or the way they described it, probably in a slightly different way than you yourself would, oh, I don’t know it’d put a different angle on it which enabled you to think through it a bit better.”

Peer support also enabled a person to make a comparison with others, which allowed them to measure their own progress, a process identified by Morris & Morris (2012), as upward and downward comparison. In addition, by comparing with those further ahead or behind, it enabled a comparison with their future or past self, helped them to set appropriate timescales and provided inspiration as Bob explained (lines 96 - 8);

“Not just in the exercise machine, they were incidental, but the major part of it was maybe to meet other and see how they recover and you think, well if they can recover, I can recover”.

This vicarious experience is recognised as a key component that helps to build self-efficacy (Bandura, 1997). Even those apparently taking a passive role, benefited from watching and listening, as Jim who was often seen sitting and resting explained (line 418); *“seeing other people doing things was helpful to me”*. Jeffrey also commented (line 132 and 150-6);

“I didn’t talk much. Other people did. They seemed to have, they were all useful. Probably the best thing to do was, was to, other people having the same trouble. I mean... Well you could listen to them. And get their experiences.”

Leo (line 78) also highlighted the importance of hearing about others experiences in the information sessions;

“Yes, because it was cross-pollination of ideas you see and chit chat and what have you.”

Guidetti et al (2009) similarly found that people were encouraged by others achievements; that by seeing others regain skills, they realised that it might be

possible for them, and that by having others witnessing their progress, provided additional motivation. Guidetti et al (2009) suggested these findings implied that rehabilitation professionals should create environments, in which participants could support each other, even though these findings were from an inpatient rehabilitation context, in which informal peer support was likely to already exist. In contrast, those attending ASPIRE have already left hospital and, without ASPIRE, would be unlikely to have any opportunity for peer support. The vast majority of attendees reported that they felt better, encouraged and more positive, even after just their first session due to the peer support.

With the ASPIRE programme, learning from others applied to caregivers as well as to stroke survivors. Caregivers found the opportunity to share the situation with others helpful in terms of knowledge as Jill (lines 64 -5) explained;

“There is a chance for you to meet other people who’ve also had strokes all at different stages to ask questions and get them answered”.

This is in line with a study by Franzen-Dahlin et al (2008), which found that a support and education programme, for spouses of stroke patients improved knowledge about stroke; however, this study also found improved psychological health for those who attended more frequently (at least five times over six months). It is recognised that the psychological health of caregivers is affected by the mental health, the impairments, and functional abilities of the stroke survivor, and that this varies with time from stroke (Forsberg-Warleby et al, 2004). It is possible, that the support provided by the ASPIRE programme, could improve the psychological health of caregivers. Although this was not a finding in this doctoral work, as only caregiver burden was assessed, and maybe in part due to the limited numbers of carer participants; it would be interesting to explore with a larger sample, whether there are benefits in the psychological health of caregivers from attending the ASPIRE programme.

Caregivers also reported that they found it helpful seeing the progress of their loved ones, as Brenda said (lines 195 -7);

“the exercise was good because from week to week you could see the progress with sort of listing out their number of yards on the machine or whatever, that was quite good”.

Some caregivers also found they benefited from seeing the progress of other participants on a once-weekly basis, which was often more noticeable than the progress of their own loved one whom they were with on a daily basis; as Daniel said (line 105 – 110 & 78 - 86);

“There again, there’s always somebody worse off than yourself.....And you can see how they’re coping with it and are pulling through. That’s the nice thing about it that they’re improving. They might not get back to 100%. ‘Mary’s not back to 100% but she’s not far off. But I thought the programme was excellent because not only was I watching ‘Mary’ progress, I was watching the progress of the others that were more serious stroke victims....And how they were gradually improving. I mean just picking something up, a square up and trying to get it into a square box. To me, that was easy for us but to somebody that’s got a little bit of brain damage....it’s difficult and I was watching people like that, that were gradually over the 12 weeks, improving.”

Recovery was not about returning to a former self, but instead, establishing a new post-stroke identity. Introducing new participants to existing participants, with whom they appeared to share common interests, as opposed to just being a fellow stroke survivor, seemed to support new starters to form bonds with existing participants. This also stimulated participants to consider their identity; as ‘Gordon’ explained; I’m not just the bloke with the stroke.

For those left with significant impairments and having to make adaptations, aspects of a new identity were inevitable, and over time individuals began to realise which aspects of their previous identity could be salvaged and which needed to change. ‘Martin’, a double glazing salesman in his forties, whose stroke had left him using a wheelchair due to severe ataxia recognised when he started the ASPIRE programme that, due to intermittent post-stroke seizures, his identity as a person who drove expensive vehicles and helped out with carnival was under threat. Another aspect to his identity had been his articulate banter; despite residual dysarthria, this had remained intact; as he accurately informed me; he still had the gift of the gab. As a health professional, attempting to support those after stroke to establish their new identity, I realised it was essential to remain flexible; as it was not always clear from the outset to myself, the stroke survivor or their family members, which aspects of a stroke survivor’s identity were core and non-

negotiable and which aspects were peripheral to their sense of identity (Robison et al, 2009).

While it is recognised that a significant proportion of those after stroke have been unable to resume ‘valued activities’ (Robison et al, 2009), due to a variety of reasons, including cognitive or physical limitations, fatigue and environmental limitations; even those who had made a full recovery from their stroke physically, cognitively and functionally, reported that they were no longer felt like the same person, that the stroke had changed them forever. This was discussed at a recent ASPIRE information session, and the consensus of all those present was that it was the impact of realising that stroke was something that could happen to them, not just other people, and that they were not immortal. Even for those with previous experience of life threatening illness such as a myocardial infarction or cancer, the sudden and unexpectedness of the stroke had forced them to reconsider their values, beliefs and behaviours. Establishing a new post-stroke identity was a key process for individuals, in moving forward after stroke to become their future selves.

5.6 Moving forwards after stroke – becoming future self

As individuals continued to move forward after stroke to become their future self, there were a number of additional facilitating factors that helped to support and sustain that progress, including; a progressive individual exercise programme; identification of health improvements that had occurred due to behaviour change; and self-management of rehabilitation. For all participants, one critical element was support and feedback, which enabled them to track their progress in these factors, towards a life they liked. In a qualitative study of neurologically impaired adults including stroke, Dixon et al (2007) also found that a crucial motivating and mood enhancing factor could be the recognition that improvements and task mastery (Bandura, 1997) were linked to the rehabilitation an individual had undertaken, though this was easier if progress was fairly rapid. The other critical element was the confidence and self-efficacy, to identify and solve issues and problems independently, without relying on professional support. The level to which an individual is able to do this, is an indication of a positive outcome from rehabilitation (Jones et al, 2009). Although the Stroke Self-Efficacy Scale did not

show statistically significant improvements in phase 2, increased confidence was reported by those attending the ASPIRE programme from the interviews in phase 1. The confidence and ability to both monitor progress and identify ways of maintaining that progress are illustrated by the following quote from Sheila (lines 150 - 155);

“I think, I think I’m doing pretty well. I use the stairs as often as I can. I make a point of rarely using the cloakroom downstairs. I’d rather go upstairs and use my lavatory upstairs to make sure I keep climbing the stairs. The fact that I walk more and the gym every Monday afternoon. I missed a couple because I was away with my daughters, and I really feel it if I miss it, the next time I go down to the town the walking is more difficult so the gym is really important to me”.

Progressive individual exercise programme

Those attending the ASPIRE programme reported that a flexible, responsive, progressive, exercise programme, individually tailored to their needs (Gordon et al, 2004; Best et al, 2010), including aerobic exercise (Billinger, 2010), supported them to become their future self. As Dixon et al (2007) found in relation to neurological rehabilitation, an important aspect to the exercise programme was the feedback about progress; Matt supported this view (lines 257 – 259);

“Well from a fitness point of view I could tell when I could walk faster and walk longer and er so the machines had the information on and we would record how long I’d been at it and so I could see that I was getting stronger each week.”

In contrast to the recommendations by Best et al (2010), the exercises carried out during the ASPIRE programme tended to all be circuit based; were once weekly rather than three times each week, and also tended to require the gym based equipment, rather than be the same ones recommended for a home exercise programme such as step ups or free weights. This approach reduced the likelihood of individuals making negative comparisons with each other, and also allowed individuals to see greater improvements each week, than if they had been doing the same exercises as they were doing at home several times a week. This approach appeared to not only be more motivating, but also enabled individuals to take more responsibility for their own progress, rather than being dependent on the group situation.

Harry explained in detail how he not only measured his progress but also adapted his exercise programme (lines 214 – 220);

“The exercise bikes, I found that was good I enjoyed them, got on with that. I did find that I could by setting the programme I could keep up the improvement, reach a reasonable standard and each week make sure that I didn’t... well hopefully start to improve on it and you make a quick improvement and then subsequent weeks obviously the level is only moderately improving, but you hope, at least I made sure, I don’t think in any of the exercises did I fall back, I was, I continued on a slightly up curve which is what I thought I wanted to do.”

During ASPIRE, stroke survivors and caregivers are encouraged to take responsibility for the pace at which they progress their exercises, so they learn to identify their own limits.

Others (Dixon et al, 2007; Reed et al, 2010) have also found that a flexible approach, allowing people to ‘push their own limits’, enables people to develop their confidence, in parallel with their increasing physical abilities. This is key, as lack of confidence in physical abilities, has been found to limit activity and participation levels (Rittman et al, 2004); whereas, increased levels of daily activity are thought likely to reduce risk of recurrent stroke (Hankey et al, 2002; Hackam & Spence, 2007) and have been shown to be associated with a better health-related quality of life (Rand et al, 2010).

Health improvements through behaviour change

Some, though not all, ASPIRE participants began to see improvements in their health, as a consequence of successfully planning, and then implementing, behaviour change. A recent example was ‘Kevin’, who shone with an inner glow of pride, when he realised at his last ASPIRE session, that his increased levels of physical activity and changes to his eating patterns had resulted in a 5 kilogramme weight loss, combined with a 2 inch reduction in girth. This gave him the boost, to set new goals he felt confident of achieving, before his review appointment.

Many others, in addition to those involved in phase 1 and 2 of the research, also achieved health improvements through behaviour change; predominantly increased physical activity levels. Most of those interviewed in phase 1, had

sustained their increased physical activity levels long term, as they reported still exercising regularly, when interviewed, at between 3 and 12 months after attending the ASPIRE programme. This would be regarded as the post-adoption stage in the transtheoretical model of behaviour change, with those having exercised for less than 6 months being in the ‘action’ stage, and those exercising for more than 6 months being regarded as being in the ‘maintenance’ stage (Garner & Page, 2005). Similarly, Howarth & Young (2009) found participants, with a variety of acquired neurological pathologies, sustained physical activity levels long term, after participating in their programme, in which participants were also able to gain confidence to exercise, in a group setting.

Self-management of rehabilitation

Some stroke survivors attending the ASPIRE programme had moved onto self-management of rehabilitation very quickly after their stroke, and were already wanting to take control of their own rehabilitation and plan their route to their future self even whilst still an inpatient; as Bob explained he found being in hospital very frustrating;

“Well I wanted to get home because I felt I think in the hospital they do everything for you, it’s no place to get better, in a roundabout way, because you can never sleep at night, there’s always noise, lights on, rattling around and so on. And it’s very difficult to sleep at night and the only exercise you get was to go to the toilet, undo the door and come back. And I felt well I’d be better off at home because, because there’s more things I can do with my hands and my feet, there’s the stairs and other types of things, make a cup of tea and I really wanted to get home as soon as possible, and that has helped me a lot I think more than just being in hospital.”

For others it took longer. In marked contrast to those interviewed one month after discharge following stroke by Rittman et al (2004), who took a much more passive role, waiting for the passage of time until recovery took place; the vast majority of those attending the ASPIRE programme succeeded in playing an active role in the self-management of their rehabilitation and recovery process. This more active approach to rehabilitation, by those who have attended the ASPIRE programme, is likely to be due to the programme supporting self-management, which has been shown to increase self-efficacy (Jones & Riazi, 2011).

In order to maintain this sense of ownership of the recovery process, intermittently, during their ASPIRE journey, each participant had their progress reviewed, revised and challenged, and prior to the final week of the 12 week programme, participants were asked what their plans were for after the ASPIRE programme. By the final session, most participants had a plan to continue exercising, either by regular walking, or by attending the local gym, and if requested, a referral was made for the exercise on prescription scheme. Participants were also encouraged to continue setting themselves short and long term plans for the future. One example was Pam, who had recently finished ASPIRE, had taken medical retirement from her role as a lecturer on the advice of her Speech and Language therapist, and who was also unable to continue her previous hobby of horse riding. Between finishing the 12 weeks of ASPIRE and returning for a review appointment a few weeks later, she had found herself a part time administrative job, become a volunteer supporting her local stroke club and a regular volunteer for Riding for the Disabled. Taking responsibility for self-managing their rehabilitation, supported individuals to forge a new identity and become their future self, without being dependent on on-going support. As Jill succinctly put it (lines 115-6);

“You need it and then it gives you what you need and then you kind of, you graduate from it”.

Not everyone achieved this during their attendance at ASPIRE, and their progress after stroke faltered. For example Jim, struggled to maintain his progress; within two months of completing ASPIRE he found it increasingly difficult to maintain his ability;

“But initially I was able to...really, really well do what I was before....but I can't now. I mean, it's not very far up to this end of town, and I was walking up there....to pick up the papers in the morning, but I can't do that now. It didn't happen overnight. It's just a feeling of great insecurity and apparently physical restriction, it wasn't painful physically. I've retrogressed.”

A clue to this might be his attitude to participating in the ASPIRE programme, as identified by his wife Eileen;

“I think also, going into the ASPIRE group the fact that he knows he's going to see you on Thursday, he's got to do something. He can't just think I'll put it off until tomorrow”.

Although at the time he appeared to be making good progress, he was relying on others to provide external feedback and motivation, and had not reached the point at which he could self-manage his rehabilitation and on-going progress.

This need for self-reliance was recognised as an important quality in the rehabilitation process, by all but 2 of the 24 participants, in a study by Dixon et al (2007). This study only included those aged 16 to 65, whereas Jim was much older (83), which may have been a factor in his more passive attitude. His attitude may also have reflected his pre-stroke personality, or been due to low mood. Ensuring participants have reached the point where they can self-manage their on-going rehabilitation, has become an important focus of the ASPIRE programme. As Ellis-Hill et al (2009) also found, when exploring perspectives of discharge from hospital following stroke, it was essential that participants felt informed and supported, in order to maintain the momentum of moving forward after stroke. Jones et al (2008) ensured that those with stroke, felt both informed and supported, by training staff to support the use of a 'patient-held' workbook in a self-management programme.

5.7 Strengths and Limitations

This reflection aimed to understand the processes involved, in moving forward after a stroke, in order to develop an interpretive theoretical framework, to guide clinical practice, with stroke survivors and their caregivers. This was carried out using interview data from stroke survivors and caregivers, plus observations and comments recorded in my 'praclog' and 'doclog', over the course of many years, working with those with stroke and their family members. A strength is the reflexivity; rather than just being based on historical data, this reflection draws on interactions documented in a research diary 'doclog', in addition to those stroke survivors currently or recently attending the ASPIRE programme, and also others at earlier or later stages in their stroke journey, (documented in my 'praclog'). Informal checking of this reflection with stroke survivors helped to strengthen its validity, and as the reflection is illustrated by extensive quotes, it allows the reader to make their own judgements about the authenticity of the reflection.

A limitation to this reflection is that the interview data used from phase 1, was gathered with the aim of identifying the impact of the ASPIRE programme, rather than the processes within it. A further limitation is that this reflection is by the author who developed the ASPIRE programme, and is also involved on a weekly basis in delivering the programme, so is subject to interpretive bias. In addition, all of those considered in this reflection had received their stroke care, from a single district general hospital, in a rural area of South West England, and many had attended the ASPIRE programme. Based on these limitations, the findings from this reflection cannot be generalised beyond the local stroke population involved; however, do offer some tentative implications, based on implementation in practice, for the way health professionals can support individuals to move forward after stroke.

Although developed pragmatically, it seems that the ASPIRE programme has supported the vast majority of its attendees, to move forward after stroke. The enabling processes identified and listed below, could be provided through an ASPIRE programme, or could be used to guide clinical practice within existing stroke service provision.

- Reassurance & Empathy
- Self-management of rehabilitation
- Improved mood
- Motivation, encouragement and positive attitude
- Health improvements through behaviour change
- Appropriate goal planning
- Peer support and learning from others rather than isolation
- Confidence and self-efficacy
- Progressive individual exercise programme

Table 51 compares these enabling processes with the current national guidelines for rehabilitation after stroke (NICE, 2013), which tend to be based on a traditional approach to rehabilitation rather than a ‘life-thread’ approach (Ellis-Hill et al, 2007). The key difference appears to be that the national stroke guidelines tend to have the stroke survivor as a passive recipient of professional

attention, with a focus on tasks to be done; in contrast to the enablers identified, that support someone to move forward after stroke, which focus on behaviours, attitude and approach.

For instance, in terms of goal setting, the national guidelines prescribe; what should be done, when and indicate the content, rather than the manner, in which goal setting should be approached. The section on information giving is similarly didactic and paternalistic, rather than the person with stroke being in control. Health behaviour change is identified in terms of professionals giving information, rather than supporting the individual with stroke, to develop the skills and identify the knowledge needed themselves. Self-management of rehabilitation, is described in the guidelines in terms of what the multi-disciplinary team should do to, and with, the person with stroke, rather than what they can do for themselves. Exercise programmes may be ‘independent’, but in the national guidelines are prescribed by the physiotherapist, communicated to an exercise provider and only the problems that may arise, such as shoulder pain, identified as being important to communicate to the stroke survivor. The approach outlined in the guidelines does not enable the stroke survivor to direct his/her own journey after stroke; instead it continues to make them dependent on health professionals.

Based on this reflexive review, supporting self-generated goal planning, based on a ‘life-thread’ approach, may improve outcomes, including from stroke survivors’ perspectives, leading to a life after stroke that includes both rehabilitation (‘a life I like’), and secondary prevention (‘a life to live’).

Table 51: Processes that support someone to move forwards to life after stroke

| Processes in ASPIRE programme that support enablers | Stroke rehabilitation guidelines (NICE, 2013) |
|--|--|
| <p>Appropriate goal planning</p> <p>Empathetic stroke specialist staff able to support and guide stroke survivors to generate and achieve their own goals</p> <p>Relaxed approach</p> <p>Effective interpersonal and communication skills</p> <p>Compassion, understanding and a positive but realistic attitude</p> <p>Reassurance & Empathy</p> <p>Motivation & encouragement</p> | <p>1.2.8 Ensure that people with stroke have goals for their rehabilitation that:</p> <ul style="list-style-type: none"> • are meaningful and relevant to them • focus on activity and participation • are challenging but achievable • include both short-term and long-term elements. <p>1.2.9 Ensure that goal-setting meetings during stroke rehabilitation:</p> <ol style="list-style-type: none"> 1. are timetabled into the working week 2. involve the person with stroke and, where appropriate, their family or carer in the discussion. <p>1.2.10 Ensure that during goal-setting meetings, people with stroke are provided with:</p> <ul style="list-style-type: none"> • an explanation of the goal-setting process • the information they need in a format that is accessible to them • the support they need to make decisions and take an active part in setting goals. <p>1.2.11 Give people copies of their agreed goals for stroke rehabilitation after each goal-setting meeting.</p> <p>1.2.12 Review people's goals at regular intervals during their stroke rehabilitation</p> <p>1.11.3 Encourage people to focus on life after stroke and help them to achieve their goals. This may include:</p> <ul style="list-style-type: none"> • facilitating their participation in community activities, such as shopping, civic engagement, sports and leisure pursuits, visiting their place of worship and stroke support groups • supporting their social roles, for example, work, education, volunteering, leisure, family and sexual relationships • providing information about transport and driving |

| Processes in ASPIRE programme that support enablers | Stroke rehabilitation guidelines (NICE, 2013) |
|--|--|
| <p>Peer support & learning from others rather than isolation. Improved mood, confidence & self-efficacy.</p> <p>Involvement of carers</p> <p>Availability of role models and ‘experts’ - stroke survivors including volunteers further on in their stroke journey giving opportunities for peer support, learning from others and vicarious experience.</p> <p>Relaxed approach</p> <p>Effective interpersonal and communication skills</p> <p>Compassion, understanding and a positive but realistic attitude</p> <p>Reassurance & Empathy</p> <p>Motivation & encouragement</p> | <p>Information giving</p> <p>1.2.6 Take into consideration the impact of the stroke on the person's family, friends and/or carers and, if appropriate, identify sources of support.</p> <p>1.2.7 Inform the family members and carers of people with stroke about their right to have a carer's needs assessment</p> <p>1.3.1 Working with the person with stroke and their family or carer, identify their information needs and how to deliver them, taking into account specific impairments such as aphasia and cognitive impairments. Pace the information to the person's emotional adjustment.</p> <p>1.3.2 Provide information about local resources (for example, leisure, housing, social services and the voluntary sector) that can help to support the needs and priorities of the person with stroke and their family or carer.</p> <p>1.5.2 Support and educate people after stroke and their families and carers, in relation to emotional adjustment to stroke, recognising that psychological needs may change over time and in different settings.</p> |
| <p>Health improvements through behaviour change</p> <p>Support and feedback to track progress and move towards a life they like after stroke</p> <p>Development of problem solving skills</p> <p>Interactive access to information in a variety of formats</p> | <p>1.3.1 Working with the person with stroke and their family or carer, identify their information needs and how to deliver them, taking into account specific impairments such as aphasia and cognitive impairments. Pace the information to the person's emotional adjustment.</p> <p>1.3.2 Provide information about local resources (for example, leisure, housing, social services and the voluntary sector) that can help to support the needs and priorities of the person with stroke and their family or carer.</p> |

| Processes in ASPIRE programme that support enablers | Stroke rehabilitation guidelines (NICE, 2013) |
|---|---|
| <p>Self-management of rehabilitation</p> <p>Support and feedback to track progress and move towards a life they like after stroke</p> <p>Development of problem solving skills</p> <p>Interactive access to information in a variety of formats</p> <p>Flexible responsive individually tailored service provision</p> <p>Reassurance & Empathy</p> <p>Motivation & encouragement</p> <p>Compassion, understanding and a positive but realistic attitude</p> | <p>1.1.4 Throughout the care pathway, the roles and responsibilities of the core multidisciplinary stroke rehabilitation team should be clearly documented and communicated to the person and their family or carer.</p> <p>1.1.5 Members of the core multidisciplinary stroke team should screen the person with stroke for a range of impairments and disabilities, in order to inform and direct further assessment and treatment</p> <p>1.2.3 A comprehensive assessment of a person with stroke should take into account:</p> <ul style="list-style-type: none"> • their previous functional abilities • impairment of psychological functioning (cognitive, emotional and communication) • impairment of body functions, including pain • activity limitations and participation restrictions • environmental factors (social, physical and cultural). <p>1.2.13 Provide information and support to enable the person with stroke and their family or carer (as appropriate) to actively participate in the development of their stroke rehabilitation plan.</p> <p>1.2.14 Stroke rehabilitation plans should be reviewed regularly by the multidisciplinary team. Time these reviews according to the stage of rehabilitation and the person's needs.</p> <p>1.2.15 Documentation about the person's stroke rehabilitation should be individualised, and should include the following information as a minimum:</p> <ul style="list-style-type: none"> • basic demographics, including contact details and next of kin • diagnosis and relevant medical information • list of current medications, including allergies • standardised screening assessments • the person's rehabilitation goals • multidisciplinary progress notes • a key contact from the stroke rehabilitation team (including their contact details) to coordinate the person's health and social care needs • discharge planning information (including accommodation needs, aids and adaptations) • joint health and social care plans, if developed • follow-up appointments. <p>1.11.1 Inform people after stroke that they can self-refer, usually with the support of a GP or named contact, if they need further stroke rehabilitation services.</p> <p>1.11.2 Provide information so that people after stroke are able to recognise the development of complications of stroke, including frequent falls, spasticity, shoulder pain and incontinence.</p> |

| Processes in ASPIRE programme that support enablers | Stroke rehabilitation guidelines (NICE, 2013) |
|---|--|
| <p>Progressive individual exercise programme</p> <p>Individually tailored exercise programme with encouragement to modify and progress themselves.</p> | <p>1.9.4 Consider strength training for people with muscle weakness after stroke. This could include progressive strength building through increasing repetitions of body weight activities (for example, sit-to-stand repetitions), weights (for example, progressive resistance exercise), or resistance exercise on machines such as stationary cycles.</p> <p>1.9.5 Encourage people to participate in physical activity after stroke.</p> <p>1.9.6 Assess people who are able to walk and are medically stable after their stroke for cardiorespiratory and resistance training appropriate to their individual goals.</p> <p>1.9.7 Cardiorespiratory and resistance training for people with stroke should be started by a physiotherapist with the aim that the person continues the programme independently based on the physiotherapist's instructions (see recommendation 1.9.8).</p> <p>1.9.8 For people with stroke who are continuing an exercise programme independently, physiotherapists should supply any necessary information about interventions and adaptations so that where the person is using an exercise provider, the provider can ensure their programme is safe and tailored to their needs and goals. This information may take the form of written instructions, telephone conversations or a joint visit with the provider and the person with stroke, depending on the needs and abilities of the exercise provider and the person with stroke.</p> <p>1.9.9 Tell people who are participating in fitness activities after stroke about common potential problems, such as shoulder pain, and advise them to seek advice from their GP or therapist if these occur.</p> |

5.8 Conclusions

This reflection on practice, incorporating stroke survivors and caregivers views, contributes to a wider appreciation of the processes, which may enable people, to move forwards to life after stroke. These processes include; enabling people to understand their immediate post-stroke identity; supporting them to envisage their future self; and assisting them to understand, and be able to navigate, the post-stroke landscape, through which they will be moving, towards their future self. Supporting individuals (and their family members) to move forward after stroke, towards ‘a life they like’ was also (and continues to be), a key purpose and fundamental philosophy, underpinning the ASPIRE programme. In addition, these processes aimed to support individuals, to have the skills, knowledge and experience, to be able to stay healthy after a stroke, ‘a life to live’.

Chapter 6: My doctoral journey – a reflexive synthesis on personal, practice and theory development.

6.1 Introduction

In this, the final chapter, I synthesise and critically reflect on, my doctoral journey including dissemination to date, and areas for future research; and summarise **my overall original contribution to knowledge, on supporting life after stroke, in terms of, rehabilitation (“A life I like”), and secondary prevention (“A life to live”)**.

This knowledge was gained from undertaking a professional doctorate, which involved four interwoven complementary components; a literature review (chapter 2), a practice development project and a primary research study (chapters 3 & 4), plus a reflexive review (chapter 5).

Overall, my thesis describes, critically evaluates and reflects on, the development and evaluation of an innovative, person-centred, complex intervention, which combines rehabilitation, with facilitating self-management for secondary prevention, after a stroke. This intervention consisted of a once-weekly, twelve week, multi-factorial, stroke self-management programme, consisting of; individualised, interactive information provision, rehabilitation and exercise, in an environment of peer and caregiver support; called ‘ASPIRE’, an acronym for **A**cute stroke, **S**elf-management support, secondary **P**revention, **I**nformation, **R**ehabilitation and **E**xercise.

The doctoral components were iterative, rather than linear, with the research components, both supporting and evaluating the practice development, and the whole supported by use of the evolving literature plus structured reflection. This chapter is formed firstly of; a) **personal** reflective narrative that analyses my doctoral journey (sections 6.2- 6.4), followed by a reflective synthesis that pulls together the different elements of this professional doctorate, and analyses how they inform both **theory** and **practice**, to delineate the **original contribution** to knowledge (section 6.5), and **remaining gaps** for future research to address (section 6.6).

6.2 Introduction to reflective narrative- a doctoral journey

Although an experienced clinician, prior to this doctorate, my reflection was rarely documented, action-related, referred to as “reflection-in action and reflection-on-action” (Schon, 1987); and predominantly stimulated by complex situations (Mamede & Schmidt, 2004). Despite limited evidence, to link reflection to development as a practitioner (Mann et al, 2009), there is a national drive towards competence in reflection, becoming an integral part of professional practice, to evidence learning (Paterson & Chapman, 2013).

As a pragmatist, I realised I needed to start to document my reflections, in a structured way, in order to begin the iterative processes of reflection. Rather than getting stuck in a loop, where I repeated the same behaviours; by having a written reflective log, new experiences triggered the revisiting of previous reflections, to enable the vertical dimension of reflection (Mann et al, 2009). This deeper analysis, supported my growth as a practitioner, by allowing new perspectives of links and structures, through the processes of association, integration and critical synthesis.

Bolton (2005) suggests using a narrative style of reflection, in order to develop skills and reach deeper levels of reflection. I knew from personal experience, that keeping a chronological narrative, in the form of a diary, was the best way for me to ensure I documented my reflections regularly. I therefore started a doctoral diary, referred to as a ‘doclog’, and a practice development diary, ‘praclog’. I have used excerpts from these reflective diaries, to support this reflexive review.

A number of authors (Wellington et al, 2005; Holloway & Walker, 2000; Doncaster & Thorne, 2000) advise that before starting a doctorate, it is important that a person reflects on, and is clear about what motivates them to undertake that doctorate. They also recommend reflecting on personal and professional experiences, including those of studying and research, which may influence their attitudes, beliefs, skills, values and concerns, and thus impact their doctoral journey. In addition, Wellington et al (2005) suggest that a process of reflecting on life history, prior to starting a doctorate, enables an individual to gain insight;

to understand the context and purpose of undertaking the doctorate, and to be able to articulate their “researcher positionality”.

Although at the time I was uncertain what this really meant, it seemed logical to start my ‘doclog’ by reflecting on some of my life and career history, thus setting the context for my doctoral journey. Writing this reflexive synthesis several years later, I am indebted to those wise authors who stimulated me to capture that snapshot in time, which I have been able to draw on to analyse my developmental journey. I start by describing some of the context in which I started this professional doctorate.

6.3 Doctoral journey – setting the context

In 2005, 15 years after qualifying as a physiotherapist, I was appointed to a post as a consultant physiotherapist, working in a small, 300 bedded, acute NHS hospital, which serves a population of 180,000, in a predominantly rural area in South West England. Prior to this, I had gained a wide range of experience and qualifications; including service development roles, clinical expertise, a MSc in neurological physiotherapy, plus experience lecturing on undergraduate and postgraduate physiotherapy courses. A number of those roles made me reflect on how physiotherapists, at that time, treated those with long term conditions, such as stroke.

Physiotherapists at the time tended to behave as experts in the management of stroke. When working as a younger physiotherapist, like many UK physiotherapists at the time (Davidson & Waters, 2000), I had taken an eclectic approach, to the rehabilitation of those with movement problems due to neurological pathologies. The most common approach was one which emphasised a hands-on approach to facilitation and inhibition of normal movement, based on analysis of movement deficits (Bobath, 1990) and which was taught through attendance at a 3 week course. I was delighted to be funded to attend a ‘Bobath’ course, hoping to significantly increase my skill levels. Unfortunately, I felt that I learnt nothing I could take away with me, as the course focussed on developing advanced clinical skills, through supervision by expert clinicians of patient treatment sessions, rather than principles I could apply to my own patients. In

hindsight, I was beginning to understand the limitations of an ‘apprentice’ style model of learning, though had not yet realised how reflection could support me to become an advanced practitioner. Serendipitously, I already knew one of the trainee tutors on the course, and when I confided my frustration in her, she recommended I consider an academic approach to advancing my practice.

This was a pivotal point in my career, as a few months later, I started a part time MSc in neurological physiotherapy, which enabled me to develop a much greater, and more in-depth knowledge of the evidence base, supporting my clinical practice. During my MSc studies I developed an interest in a self-management approach to rehabilitation, which supported and empowered those with stroke to manage their own condition, rather than becoming therapist-dependent. My MSc research project used a multiple single case study methodology, to investigate the impact of an exercise programme, on gait speed and upper limb function late after stroke. This ‘hands-off’ approach appeared to be in conflict, with the usual physiotherapy approach at the time.

Physiotherapists at the time tended to focus on the physiotherapy agenda, rather than life after stroke, as I discovered when seconded to a role of ‘stroke care pathway project manager’. This involved mapping existing services for those with stroke, to identify gaps in service and duplications, which would inform the planning of a revised stroke pathway. I gained permission from existing service providers, to talk to those after stroke, their families and those providing services. The more I found out about the existing services, the more passionate I became about improving those services; as I was shocked by stroke survivors’ views, that the current service provision stifled their ability to self-manage, and made them dependent on therapists (Neal, 2005). I also began to realise, how powerful qualitative data could be, in triggering change, as the views about stroke services expressed by those with stroke, were diametrically opposed to the views of many clinical staff, about the service they thought they were providing, and that they thought patients should have. This was the start of me recognising, the contribution and value of qualitative, as well as quantitative, research to professional practice.

The views expressed by stroke survivors, were echoed by groups and individuals with neurological conditions, such as multiple sclerosis, whom I met in a subsequent role, as neurology care pathway lead. They described a health care system, that they felt was unable to support self-management, despite the efforts of many clinicians, and the widespread implementation of initiatives such as the “Expert Patient Programme” (EPP). Those with neurological conditions that I interviewed expressed the view that the EPP had limited usefulness, due to its generic nature, and lack of adaptability for those with communication or cognitive difficulties. Although the EPP was shown by Kennedy et al (2007) to be effective in improving self-efficacy in those with long term conditions, it was not specified whether any of those in this study had neurological conditions. In addition, evaluation has shown that the EPP has some limitations, due to its focus on the way patients should change, rather than the way services should be provided (Corben & Rosen, 2005).

These care pathway roles, and a short secondment as an expert advisor for the Healthcare Commission, inspecting stroke services elsewhere in the country, gave me the opportunity to reflect on my own, and others’ professional practice. At the time, I was fairly confident that I supported self-management. In hindsight, my practice was predominantly focused on enabling people to continue their own physical rehabilitation programme between physiotherapy sessions, rather than supporting them to develop the skills and knowledge, to manage their life, living with a neurological condition.

It was at this stage in my development, that I was successful in gaining a post as a consultant physiotherapist. In common with other non-medical consultant practitioner posts, my role combines teaching, research, service development and expert clinical practice (Chartered Society of Physiotherapy, 2005). A key requirement highlighted in the person specification for my role, was that I should have or work towards gaining a doctoral qualification. A key objective of my role was the reduction of emergency bed days i.e. the number of days occupied by people admitted as an emergency, rather than electively.

My background and interest, combined with the political focus at the time (Department of Health, 2005a), meant that finding a way of supporting those with long term conditions to self-manage, seemed a logical way of achieving both my objective, and the doctoral qualification. Around this time, 'Promoting Optimal Self-Care', a handbook, developed in my local strategic health authority, was published; this handbook provided evidence and advice on how to support self-management (Tomkins & Collins, 2006). This resonated with me, and gave me ideas on how to translate national policy into local action.

From my previous experiences, I was aware of how little this type of self-management approach had translated from research, into practice, despite evidence that all aspects of the health service should support individuals, living with a long term condition, to self-manage, and despite being mainstream health policy (Department of Health, 2006). Keen to take a lead in encouraging all clinical staff to support patients to self-manage, and convinced by the evidence available, I held a series of launch events for the 'Promoting Optimal Self-Care' handbook, starting with a staff group that I assumed would already have a mind-set that was receptive to this approach; rehabilitation staff. They demonstrated a surprising (to me) range of reactions, which varied from hostility ("that's asking far too much of our patients"), to much more frequently, complacency ("well you're preaching to the converted as we do all that already"). Many medical and nursing staff expressed disinterest, and the dominant mind-set was that supporting self-management was purely the responsibility of primary care. It was clear that there was some way to go, before supporting patients to self-manage became embedded in the culture of clinical practice, within the organisation. This type of response is well recognised, as a challenge to introducing an ethos of person-centred care (Ahmad et al, 2014).

My perception was that people appeared to be disempowered and least likely to self-manage, when in contact with secondary care, particularly as inpatients. This is unsurprising, as it is recognised that those with lower levels of activation and ability to self-manage, are more likely to be admitted to hospital (Hibbard & Gilbert, 2014). Reflecting on this, I concluded that supporting people with long term conditions to "self-manage", should be embedded within the way services

were provided, by the acute hospital for which I work. Perhaps somewhat naively, I decided to develop a model of practice that supported self-management, so that I could provide a hospital based exemplar that would inspire others to follow suit. The dilemma was then which area of practice to use; a disease area with a strong evidence base such as respiratory conditions, or an area in which I had clinical expertise. I agreed with Jones (2006), who suggested that research was needed to establish whether strategies used in other chronic conditions, could be effectively used in neurological conditions. This would also allow me to be a role model in my area of clinical expertise, which would increase the credibility of the project. As a pragmatist, I realised that focussing my doctorate on something I had to do for my job anyway would make it more meaningful, economise on effort and should keep me motivated. I therefore decided to focus my doctoral studies on supporting self-management in neurological conditions.

The National Service Framework for Neurological and other long term conditions (Department of Health, 2005b) suggested that people with all long term conditions, including those of neurological origin, should be supported to self-manage; however, the focus of the evidence cited in this framework related to diabetes plus cardiac, respiratory and musculoskeletal conditions, with a scarcity of evidence in relation to self-management in those with neurological conditions. The heterogeneity of neurological conditions meant that developing a model of practice to support self-management, in those with all types of neurological conditions, might be impractical. I hypothesised that since stroke produces similar impairments (such as movement, communication and cognitive difficulties) to many other neurological conditions, that developing a model of practice to support self-management after stroke, might provide valuable information on how to support self-management, in people with a broader range of long term neurological conditions.

I therefore started the doctoral process seeking to answer the research question 'Does current clinical practice after stroke support self-care; Perceptions of stroke survivors and clinicians'; in preparation for a possible randomised controlled trial of a novel intervention. The aim of the practice development project to explore;

‘Can self-care be supported after stroke from an acute hospital setting?’, was to develop that novel intervention. As such, although the practice development and research study were linked, they were not interdependent, and as a local audit (table 1) had demonstrated a clear need to change practice, I started with the practice development element of the doctorate.

As the practice development evolved, it became clear that, although a full feasibility study would not be possible for the research element of the doctorate, a great deal could be learned, from formal evaluation of the processes and outcomes, of the practice development. In hindsight, one approach would have been to use action research methodology, which seeks to answer a specific research question through action and evaluation to produce generalisable knowledge (Lingard et al, 2008). This would have been a very useful way forward; however, at the time I was focused on providing evidence to support the development of a clinical trial, and so I did not recognise this possibility until I was almost through data collection. Looking back now, this rush to get on with action typifies my approach, both personally and professionally at that time, with a focus on practical, hands-on activity, rather than reflecting, thinking and planning in an academic way. As I started on my doctoral journey, I had no idea of the turbulent personal and professional growth I would experience in the years ahead. In the next section, I evaluate my personal and professional development, during my doctoral journey.

6.4 Doctoral journey – personal and professional development

Doncaster and Thorne (2000) drew up a table specifying doctoral level capabilities (see Table 52). To help me reflect on my own development, I have used their table to gauge aspects of my development, which I will discuss in more detail below. Having completed an MSc in neurological physiotherapy; I had gained skills including critical appraisal, analysis, evaluation, synthesis, computer literacy, effective, time efficient study skills. I also had theoretical knowledge of a number of research methodologies, but very limited practical experience. However I realised I had ‘deeper’ skills to develop so knew it was important to rate my skill levels as I started on this doctoral journey.

Table 52: Doctoral level skills

| Category of doctoral level skills | Capabilities | Initial score 1 – 5* | Final score 1 – 5* |
|---|---|---------------------------------|-------------------------------|
| High level transferable skills | a. Reflection on own & others professional practice | 1.5 | 5 |
| | b. Awareness of political implications of doctoral work | 2 | 5 |
| | c. Self-directed & self-managed learning | 1.5 | 5 |
| | d. Ability to tackle unpredictable problems in novel ways | 2 | 5 |
| | e. Ability to engage in full professional and academic communication with others in their field. | 1.5 | 5 |
| | f. Ability to evaluate, select, combine and use a range of research methods and contribute to the development of applied research methodology | 2 | 5 |
| High level cognitive capabilities | g. Interdisciplinary knowledge | 4 | 5 |
| | h. Ability to work at current limits of theoretical and / or research understanding in particular fields. | 3 | 5 |
| | i. Ability to deal with complexity and contradictions in the knowledge base. | 3 | 5 |
| | j. Ability to synthesise ideas and create responses to problems that redefine or extend existing knowledge. | 2 | 5 |
| | k. Ability to evaluate alternative approaches. | 3 | 5 |
| Capabilities related to operational context | l. Ability to function in complex, unpredictable and specialised work contexts which require innovative study. | 2 | 5 |
| | m. Autonomy within bounds of professional practice with high levels of responsibility for self and others. | 4 | 5 |
| | n. Awareness of ethical dilemmas likely to arise in research and professional practice. | 4 | 5 |
| | o. Ability to formulate solutions in dialogue with stakeholders. | 3 | 5 |

*Rating scale from 1 through to 5 where; 5 = performing at doctoral level and 1= significant gaps in skills or knowledge.

I could see the areas that required the most development, and with my preference for an activist learning style, assumed that the process of **doing** the practice development, and **doing** the research would help me acquire those skills. I really had no idea, that it was during the process of reflecting and writing up, that my skills would develop the most. Furthermore, even though I was undertaking a professional doctorate, I had not anticipated that I would develop in all areas of my professional and personal life, and had assumed that my development would be focused predominantly on research knowledge and skills.

Undertaking the professional doctorate allowed me to focus on theory as well as practice, and develop my skills in a number of areas including reflection, self-directed learning, communication and the ability to influence professional practice through dissemination of research evidence. I have reflected on each of these areas of development below.

Focus on theory as well as practice

I chose to undertake a professional doctorate, rather than a PhD due to my personal bias towards praxis (Wellington et al, 2005). I was also reassured by Doncaster and Thorne (2000), who suggested that those successfully completing professional doctorates, are expected to have undertaken advanced learning that produces major organisational change, and/or the development of professional practice to an exceptional level, through practice-based projects. This felt much more aligned to my career to date, and my aspirations for the future, in being a researching practitioner; rather than a PhD designed to train me to become a professional researcher.

I was unaware when I started, quite how much I would need to, and benefit from, focusing on theory as well as practice. At the time, I tended to base my practice on applied theory in the form of published evidence. As time went on I realised that, in order to be innovative in practice, I would need to underpin that innovation with theory i.e. a “coherent and non-contradictory set of statements, concepts or ideas that organises, predicts and explains phenomena, events and behaviour” (Eccles et al, 2005, p2).

Undertaking a professional doctorate, rather than a PhD, led to me experiencing the tensions involved in being simultaneously a practitioner involved in supporting the ASPIRE programme, and the sole researcher into that programme. Initially, I wrestled with the **interplay between**, and the **separation of**, the research evaluation and the practice development project. My ‘doclog’ from the end of 2009 notes;

“It's like trying to separate the ingredients of a cake once it's been baked - I know what went into it but everything in it has been changed by the process. It would be a lot easier if I'd made a casserole - I'd still be able to identify the carrots, onions and potatoes as separate items.”

Ultimately, I realised that the research evaluation and the practice development project being so closely intertwined, were fundamental to the overall contribution to knowledge for practice. This is demonstrated in the critical reflexive review undertaken in chapter 5.

At times, the parallel journeys of professional doctorate, and consultant physiotherapist, have been a source of huge conflict and at times, been mutually supportive, serendipitous and synchronous; either way my doctoral journey has been integral to my development as a consultant practitioner. As my ‘doclog’ records;

“I was talking with (a colleague) today about my role and the difficulties of juggling NHS and university demands and was asked if studying for the professional doctorate helped to pull it all together. My immediate reaction was to say that it made it more difficult - it was just an extra thing to try and squeeze in, adding to the overall stress. In my mind's eye the doctorate was being squeezed in between or maybe being bounced between the two. When I tried to visualize this, the doctorate was like a ball bouncing between the two parts of my job like an old fashioned computer game. After I drew it, it looked more like lace holes with thread between. On reflection I suppose if you could pull the thread tight it would pull the two roles together.”

This is exactly what happened: my doctoral journey helped support and nourish my development, both as a person and in my role as a consultant practitioner.

Development of my reflective skills

Like many physiotherapists who qualified in the 1980s and 1990s, my professional development was gained through clinical experience and attending short courses led by experienced physiotherapists, rather than through reflection on practice. Although I had some experience at reflecting on my practice and those of others, I rarely documented my reflections in a systematic way, thus limiting the opportunities to develop through revisiting those reflections. The process of keeping reflective diaries during the doctorate ('praclog' and 'doclog'), enabled me to further develop my skills of reflection on my own and others practice, such that I was able to gain new insights through forming associations and the integration of ideas, arising from reviewing my documented reflections. This more structured and documented process of reflection supported me in my role as a consultant practitioner, in the doctoral process, and in the development of the ASPIRE programme.

I had not anticipated that the biggest impact of the doctorate would happen during the final writing up process. Based on my previous experience of writing up experiments, as part of my degree in microbiology, and writing up a series of case studies for the dissertation phase of my MSc in neurological physiotherapy, I naively assumed the writing up process for this doctorate would simply be documenting the research and practice development processes, rather than the transformative and deeply reflective journey I experienced. I had anticipated that it would be a task to be done, rather than a lived experience (Wellington et al, 2005).

Initially, I became frustrated at the length of time it was taking to 'write up' i.e. finish the thesis. Gradually through the process of reading, writing and reflection I began to realise, that the writing process was for me, THE most critical part of the doctoral journey (Wellington et al, 2005), and that the only way to become effective as a reflective practitioner was through being submerged in reflection (Bolton, 2005). This process of submerging myself in reflection, enabled me to develop the framework to support self-management after stroke in chapter 5. I am now regularly documenting and reflecting on practice in my continuing professional development (CPD) portfolio, which supports my discussions in

consultant practitioner peer support meetings, provides evidence of my development and also informs objective setting with my manager. I now feel I have reflective skills that will enable me to continue to progress my practice, and those of others, throughout the rest of my career as a consultant physiotherapist.

Development of self-directed learning skills

I was also becoming more confident at directing my own learning and finding ways of putting my growing skills into practice. Examples include; volunteering to review abstracts submitted for the UK stroke forum; becoming an external reviewer of research protocols and reports for the National Institute for Health Research (NIHR); and becoming local lead investigator for the AVERT phase 3 trial into very early mobilisation after stroke (The AVERT trial collaboration group, 2015). These experiences have given me in-depth knowledge of different research methodologies, and further developed my skills and confidence.

I had initially started the doctorate as an external validation of my professional role, and to 'prove' something to myself and others, over time it had become much more about my personal and professional transformation. Rather than being about the qualification, it had become far more about the skills and confidence I had developed along the way, somewhat mirroring the journey of stroke survivors through the ASPIRE programme. In a similar way to ASPIRE participants, mine had been a journey of growing realisation of gaps in my knowledge and behaviours, that were stopping me moving forward, even though when I started, I had very little idea of the direction in which I wished to progress or the potential future landscape. Having started on the doctoral journey, I began to identify achievable goals and ways of changing my behaviours and addressing my knowledge gaps. In a similar way to ASPIRE participants, ongoing feedback and the achievement of small goals helped to sustain my journey. Reflecting on my doctoral journey as a whole, the aspect I am most proud of is my much greater confidence, self-directed learning ability and ability to continue working towards this doctorate through many personal and professional upheavals. This also mirrors the development of confidence and self-management ability that many ASPIRE participants gain, despite a number of challenges, such as health issues and changes in social context after their stroke.

Development of the ability to influence professional practice through dissemination of research evidence

I have always been focused on practice development rather than theoretical development alone. A bias towards pragmatism and praxis, as well as research, underpinned my ambitions of doctoral study, as evidenced by the following excerpt from my doctoral programme application;

“In my first non-clinical post, I project-managed a whole-system change in stroke services taking an organic, patient-centred approach. Although I shared my experiences from this work at conferences and through publication in a special interest group journal (Neal, 2005), I realise that a more robust, evidence based approach would have allowed my findings to reach a wider audience. I anticipate that undertaking this programme of study will enable me to take a structured approach to the practice development project which will enable me to disseminate my learning to others.”

As I started on my doctoral journey, I had very little confidence in my abilities to engage in full academic or professional communication, either face to face, or in writing, so had not for instance spoken at regional or national conferences, or written for publication in a peer reviewed journal.

Murray (2002) suggests that one way of improving writing is to attempt to write continuously for five minutes by hand. I used this opportunity to capture my thoughts on my development as a writer at the start of my doctoral journey;

“Writing continuously in sentences for five minutes to see how many words I can generate in that time seems simultaneously bizarre, logical and challenging. Bizarre, because it is alien to all the academic writing I have done since I was about 11; logical because it proves a point about creativity being blocked by formal academic convention and allows the thoughts to just flow onto the paper, to be corrected later and drafted and redrafted; challenging because my mind wants to constantly stop, refine, reorder and change not only the content but the order, grammar and flow. I am so used to either the strict format and bullet point style of writing reports for work and the critically evaluated formal academic writing that I have probably lost some of the creativity I had as a child. Some of the critical reflection that I have had drummed into me has literally cramped my style. It is tempting to consider writing in long hand and then typing it up onto computer as I know in the past I have been reluctant to ditch carefully thought up sentences and try and incorporate them even if somewhat inappropriate.”

As I progressed through my doctorate, I gained more experience in a variety of ways of communicating through writing, including annual reports, transition document, draft chapters, a peer reviewed article for publication (Neal, 2009) and abstracts for conference presentations. Over time, I developed the ability to push through the 'reflexivity paralysis', which blocked my ability to write through self-censorship during the writing process, and began to relax and let my writing flow.

Having successfully defended my thesis in my viva, yet still being asked to rewrite this thesis, made me reflect on the need to step-back and consider the wider audience in my writing. I therefore, decided to focus on the key messages I wished to communicate from my doctoral work, and used the process of writing and submitting abstracts to some key national and international conferences, to clearly identify the original contribution of my work. This then helped me in the rewriting of this thesis, by enabling me to clarify the importance of what I had achieved, and set it in context with existing knowledge.

Throughout my doctoral journey, I have disseminated my findings, both on the practice development and the subsequent research. This has partly been through an enthusiasm to share my excitement at the impact of the ASPIRE programme on participants with others, but also to build my confidence and profile. As a consequence, I have now presented posters at international, national and regional conferences, given oral presentations at regional and national conferences and spoken on local radio about the ASPIRE programme.

The ASPIRE programme has been cited as a good practice example on the Department of Health website, been mentioned in the House of Lords and has been included in an integrative review of post-stroke secondary prevention interventions (Lawrence et al, 2015). This review identified three key themes of 'Feeling supported' 'Acquiring knowledge' and 'Gaining confidence'; which together assist stroke survivors to make positive lifestyle behaviour choices, after a stroke (Lawrence et al, 2015). These three themes resonate with those identified in the first phase of the evaluation of ASPIRE.

As a result of this dissemination process, there have been numerous visitors and enquiries, from our own and neighbouring NHS trusts, and further afield over the years. As a consequence, similar programmes have been established elsewhere. Some of our visitors have also set up their own programme in North Devon based on ASPIRE. Although integrated with their Early Supported Discharge service for stroke, their programme itself (named VISTA, not an acronym) is run along the same lines and with the same ethos as the ASPIRE programme, and has been running successfully for several years. Another group based on ASPIRE started in North Wales, following my response to a query through the interactive Chartered Society of Physiotherapy website (iCSP).

Several local community hospitals have now set up their own programme based on ASPIRE (called Life after Stroke Groups). Due to limited space and equipment in the community hospital rehabilitation facilities, fewer stroke survivors can take part in the exercise sessions, so although individually tailored they are more directed by the physiotherapist, to maximise use of the available equipment and space. I and one of our ASPIRE volunteers (Dave) are involved in providing some of the information sessions at these groups.

I have now established my identity as a consultant practitioner with a bias towards academia, particularly research, and also the service user experience, predominantly in those with stroke. This identity has resulted in the ability to have an impact at local, regional, national and international level through improving services directly, contributing to the evidence base, or supporting the development of others.

Locally, I am viewed as having a strong focus on the stroke journey from the stroke survivor and carer's perspectives, and was recently asked to run a series of focus groups with stroke survivors and caregivers, to inform the commissioning of services, for those with stroke and their caregivers, in the post-inpatient phase. I have also successfully gained funding, from the clinical commissioning group, to develop local Functional Electrical Stimulation services across the 3 NHS trust providers in the county.

Regionally, I have spoken twice at the Stroke Research Network annual conference, facilitated a session on qualitative research at the Allied Health Professionals conference, and contributed to a collaborative systematic review on stroke survivors' views on upper limb after stroke. **Nationally** the local AVERT team which I lead was highly commended in the NIHR stroke research team of the year award. I was approached to speak at the UK stroke forum, in late 2014 about ASPIRE with volunteer 'Dave', in a session on good service user involvement in stroke research. I was also successful with my abstract submissions about my doctoral work after my viva, and was invited to present both a poster and give an oral presentation on ASPIRE at the National Physiotherapy Conference in 2015.

Internationally, I was asked to give an oral presentation at the European Stroke Conference in Vienna in 2015. Late in 2015, I was invited to an inaugural meeting to form an international group of researchers involved in stroke secondary prevention, now named INsSPIRE (International Network of Stroke secondary Prevention Researchers). The aim of this group will be to raise the scientific profile of secondary prevention, as a key element of long-term stroke rehabilitation and living life with the consequences of stroke, plus build a body of evidence, and promote a person centred and/or family-centred approaches to (secondary) prevention research.

I have realised that the ability to influence professional practice is far greater than that of the evidence, and also includes the impact due to the development of my skills, as a result of my doctoral journey. The start of this realisation came in 2009, when I was asked to speak to the local strategic health authority's education commissioning group, on how doctoral study can inform practice development and improve care. I argued that the aim from my doctoral study was to become a 'scholarly professional not a professional scholar' (Doncaster & Thorne, 2000) and also a "researching professional" (Noble, 1994). I also expressed the view that it was not only the development of skills through doctoral study, but also being in an appropriate job role to allow those skills to flourish, that led to improvements in care. I expressed this as at the time there were very few consultant practitioner posts, particularly for physiotherapists.

Through developing my skills in communication through the doctoral process, I now feel able to, and have been asked to contribute to wider academic and professional issues, including speaking on latest advances in physiotherapy at a regional stroke research conference, speaking about the implementation of the NICE stroke rehabilitation guidelines at the 2013 National Physiotherapy Congress, and reviewing material for the National Institute of Health Research.

Recognising the skills I have developed during the course of this doctorate, my employers have asked me to apply those skills, to develop innovative solutions to a much broader range of unpredictable and larger-scale problems. One example was being asked to identify barriers, and propose solutions, to improving emergency patient flow through my employing NHS hospital from emergency department to discharge. Another example was identifying ways of establishing an early supported discharge service for stroke with very limited additional resources.

Currently working for one of the NHS 'New Models of Care' sites, I have been able to spread ideas about self-management into wider practice. I am involved in developing a service across all health, social and voluntary care sectors that facilitates self-management skills, in people with long term conditions. I have been involved in the design, implementation, training of staff, working with patients as a physiotherapist and evaluation of the Symphony project. A key focus has been developing and disseminating health coaching skills, to support those with multiple long term conditions, to become more activated in the management of their conditions.

6.5 Original contribution to knowledge

Informing theory

For some time, there has been recognition of the need to start treating stroke as a long term condition in terms of both rehabilitation (Cott, 2004), and secondary prevention (Morse, 2010). Lou et al (2016) recently identified that a key element in rebuilding after stroke was autonomy. This is in line with the reflective review in chapter 5, in which I identified that for a person to move forwards to life after stroke, they had to establish their post-stroke identity. In addition I identified that

three sequential key processes occurred, that led to this autonomy; firstly understanding the post-stroke landscape and their identity; secondly envisaging their future self; and finally becoming their future self. I also identified a number of factors, which acted as enablers or as inhibitors to this process. Key enablers included; reassurance and empathy; self-management of rehabilitation; improved mood; motivation, encouragement and positive attitude; health improvements through behaviour change; appropriate goal planning; peer support and learning from others rather than isolation; confidence and self-efficacy; and progressive individual exercise programmes. I concluded that an approach that supports self-generated goal planning, based on a 'life-thread' approach, may improve outcomes, including from stroke survivors' perspectives, leading to a life after stroke that includes both rehabilitation ('a life I like'), and secondary prevention ('a life to live').

The other key learning from this doctoral work in terms of theory, was that existing outcome tools, may not adequately measure new multi-factorial post-stroke interventions, such as the ASPIRE programme, that are designed to impact health behaviour change and self-efficacy.

Informing practice

There are four key messages which come from this work linked with the development of practice.

Firstly, it is important that stroke services have an enabling culture, which develops an individual's confidence, to move forward to life after stroke. A number of key facilitators of that enabling culture were identified, that included peer support and learning from others rather than isolation. Crucially this peer support can start from immediately after stroke, through providing opportunities for those with stroke and their families, to meet and talk with each other, and stroke survivor and carer volunteers.

Secondly, support for self-generated goal planning, based on a 'life-thread' approach, which develops the confidence to do everyday activities, important to

that person, may improve outcomes from the stroke survivors' perspectives. In practice, this means working closely with that individual, to understand their pre-stroke attitudes, beliefs and values, support them to plan goals and identify steps for achieving them.

Thirdly, supporting individuals to develop the confidence, knowledge and health behaviour change to reduce vascular risk, CAN feasibly be an integral and complementary part of rehabilitation after stroke. The ASPIRE programme has now been running as a rolling programme since 2007, and has been attended by the majority of people discharged directly from the author's acute stroke unit, including stroke survivors with a wide range of physical, cognitive and communicative deficits. Over the years since the ASPIRE programme started, participants have been aged from 22 to 92 and included; those with TIA or non-disabling stroke; those who are completely aphasic; those who have memory difficulties; those who are full time wheelchair users due to dense hemiplegia or ataxia; those who are tube fed; and those with low mood, anxiety or anger issues. Organising the programme with rolling start and finish dates, as opposed to a cohort start, allows participants to start in a timely way, and allows the experienced participants to support, inspire and encourage those who have just had their stroke, plus allows those who are longer since their stroke to realise the progress they have made. The involvement of past-participant volunteers can support the smooth running of the programme, plus add additional peer support.

This doctoral work has shown that it is possible to run a multi-factorial programme, to reduce vascular risk after stroke, which can bridge the gap between secondary prevention after stroke 'a live to live', and rehabilitation 'a life I like'; and also between pharmacological and non-pharmacological approaches, to modifying risk factors after stroke. This contrasts with the dominant paradigm as shown in clinical guidelines (Winstein et al, 2016), which separates rehabilitation and secondary prevention, with rehabilitation usually being regarded as an add-on component. Strong support for the integration of a biopsychosocial rehabilitative approach, into the biomedical secondary prevention world comes from Wade (2015). The latest commissioning guidance for rehabilitation (NHS England,

2016) also acknowledges that rehabilitation is now central to the way health services are delivered. In addition, the ASPIRE programme is in line with the five current areas of focus, to support people living with long term conditions, identified in the 'Realising the Value' programme (Wood et al, 2016). These areas are peer support, self-management education, health coaching, group activities and asset-based approaches to support health and wellbeing. Assets used in the ASPIRE programme include the volunteers and carers, as well as the stroke survivors themselves.

Finally, this doctoral work has demonstrated that individually tailored exercise programmes, to support both rehabilitation and secondary prevention are feasible, with groups of stroke survivors, with a wide range of physical, communication and cognitive deficits. This shows that this model may be usefully applied to usual service provision, and does not have the usual limitations of clinical trials which, by their nature, often have a very specific and limited patient group.

6.6 Future research

What is less clear, and should be considered in future research, is

- a) What is the most effective combination of components in that multifactorial programme? This could be identified through a mixed methods study, which combines a randomised, controlled trial, with a qualitative arm to seek views of participants.
- b) What is the best 'dose' of a multi-factorial programme, for those with physical, communication or cognitive deficits, to sustain long term reduction in vascular risk?' This could be identified by comparing different length interventions in a randomised, controlled trial, and following up for at least a year.
- c) What most generates an enabling culture are the attitudes, beliefs and behaviours of staff towards those with stroke. It is not just what is done, but HOW it is done. What is less clear, and should be considered in future research, is '(How) can staff be trained to provide an enabling culture?' A number of different approaches to training could be trialled, with the outcomes measured by seeking stroke survivors' and carers' views, and

also by the impact on vascular risk in those stroke survivors. Ahmad et al (2014) suggest that it is important to train whole teams not individuals, to provide real-life examples of self-management support, as many professionals already think they work in a person centred way, and also by constructively tackling resistance to change in working practice.

- d) Existing outcome tools may not adequately measure new multi-factorial post-stroke interventions, such as the ASPIRE programme. Outcome tools which are based on user experience need to be developed, to address the following identified gaps
 - (i) A tool to assess self-efficacy after stroke, in relation to participation and an extended range of functional activities, to address the ceiling effect identified with the Stroke Self-efficacy scale.
 - (ii) A user-friendly tool to assess attitudes and beliefs to health behaviour change, for use with people after a stroke.

These tools would need to be developed in partnership with stroke survivors and caregivers.

6.7 Conclusion:

In summary, the process of doctoral study has enabled me to identify the synchronicities and the tensions between the four key elements of my professional role as a consultant physiotherapist; 1) research, 2) expert clinical practice, 3) service improvement and 4) teaching. Through doctoral study, my ontological and epistemological view point has shifted, and I have embedded that shift into my researcher, personal and professional identity; which has led to a deeper understanding of my role and the ability to articulate my expertise i.e. 'finding my voice'. The process of critical reflection, whilst writing up this doctorate, has given me the confidence to express that authentic voice and articulate my overall contribution to knowledge.

Despite the challenges that existing outcome tools may not adequately measure new multi-factorial post-stroke interventions, such as the ASPIRE programme designed to impact health behaviour change and self-efficacy, the key new messages from this work are the importance of:

- An enabling culture, that includes peer support for stroke survivors and caregivers, helps individuals to move forward after stroke.
- Support for self-generated goal planning, based on a ‘life-thread’ approach, may improve outcomes from stroke survivors’ perspectives.
- Supporting individuals to develop the confidence, knowledge and health behaviour change to reduce vascular risk, can be an integral and complementary part of rehabilitation after stroke. A multi-factorial programme to enable life after stroke, should therefore include both rehabilitation “A life I like”, and secondary prevention “A life to live”.
- Individually tailored exercise programmes to support rehabilitation and secondary prevention, can be used with groups of stroke survivors with a wide range of deficits.

I now look forward to continuing to use the knowledge, skills and experience developed through this doctoral journey, into new challenges and opportunities.

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APPENDIX 1: Provisional Ethics

Somerset Research Ethics Committee
R&D Office
Musgrove Park Hospital
Taunton
Somerset
TA1 5DA
Telephone: 01823 344799
Facsimile: 01823 342780

SB/ac/08/H0205/14

18 March 2008

Ms Deborah Neal
Consultant Therapist - Rehabilitation
Yeovil District Hospital NHS Foundation Trust
Rehabilitation Department, Yeovil District Hospital
Higher Kingston, Yeovil
Somerset
BA21 4AT

Dear Ms Neal

Full title of study:ASPIRE: Acute stroke, Support, secondary Prevention, Information, and Rehabilitation & Exercise - an evaluation of a practical way of enabling those with stroke to self care?

REC reference number: 08/H0205/14

The Research Ethics Committee reviewed the above application at the meeting held on 12 March 2008. Thank you for attending to discuss the study.

Documents reviewed

The documents reviewed at the meeting were:

| Document | Version | Date |
|---|-------------------------------|------------------|
| Application | | 25 February 2008 |
| Investigator CV | Deborah Neal | 20 February 2008 |
| Protocol | 2.0 | 26 February 2008 |
| Covering Letter | 1.0 | 26 February 2008 |
| Summary/Synopsis | 1.0 | 26 February 2008 |
| Letter from Sponsor | Bournemouth University | 27 February 2008 |
| Peer Review | Anne Forster Leeds University | 16 February 2008 |
| Letter of invitation to participant | 2.0 Part 2 | 20 February 2008 |
| Letter of invitation to participant | 2.0 Part 1 Stroke survivor | 20 February 2008 |
| Letter of invitation to participant | 2.0 Part 1 Carer | 20 February 2008 |
| Letter of invitation to participant | 2.0 Part 1 Staff | 20 February 2008 |
| GP/Consultant Information Sheets | 1.0 Part 1 Stroke survivor | 26 February 2008 |
| GP/Consultant Information Sheets | 1.0 Part 2 | 26 February 2008 |
| Participant Information Sheet: Part 1 Staff | 2.0 | 02 February 2008 |
| Participant Information Sheet: Part 2 | 2.0 | 20 February 2008 |
| Participant Information Sheet: Part 1 Stroke survivor | 2.0 | 02 February 2008 |
| Participant Information Sheet: Part 1 Carer | 2.0 | 02 February 2008 |
| Participant Consent Form: Part 1 Carer | 2.0 | 02 February 2008 |
| Participant Consent Form: Part 2 | 2.0 | 20 February 2008 |
| Participant Consent Form: Part 1 Staff | 2.0 | 02 February 2008 |
| Participant Consent Form: Part 1 Stroke survivor | 2.0 | 02 February 2008 |
| CV for supervisor | Prof. Ahmed Khattab | |

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to a meeting of the sub-committee of the REC.

Further information or clarification required

1. In discussion with the Committee it was clarified that:
 - a. The possibility of coercion has been considered and care will be taken to ensure that participants do not feel under pressure to take part in or continue with the study.
 - b. Arrangements are in place to help those stroke survivors with communication difficulties to discuss the study on the telephone if they wish.
 - c. The interview time is flexible and may take up to two hours.
 - d. The support systems for the stroke survivors and their carers are already known and contact will be made with them if necessary.
 - e. 'Stroke survivor' is the preferred terminology among the patient group.

In addition:

2. The participant invitation letters, information sheets and consent forms should be presented on University headed paper. Somerset Research Ethics Committee should be referenced as the approving REC.
3. The part 1 stroke survivor invitation letter appears to be mislabelled as the wording refers to 'health & social care staff's perspectives' and 'your role.' The correct version of the invitation letter should be submitted to the Committee for review.
4. More information should be included in the information sheets about the 'usual referral processes' which may be accessed if a participant or their carer becomes very distressed during the interview.
5. All the information sheets would benefit from a more complete description of the types of topics to be covered in the interviews.
6. The answer to question A30 of the application form indicates that if participants withdraw from the study the data collected about them will be retained and used. This is not satisfactory. If any participant withdraws, their data must not be used and must be discarded and the information sheets must state that this will be so.
7. Although the interviews are not intended to provide a forum for complaints and ground rules should be established at the start to make this clear, arrangements should be in place to deal with the possibility of disclosures of poor staff practice in case they arise. Details of the arrangements, which may involve confidential discussion with your line manager and onward referrals as necessary, should be outlined in the information sheets.
8. An indication is required of the type of statistics such as gender, age, stroke severity, which will be collected for the study.
9. Anonymised data from the study should be stored for seven years.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 16 July 2008.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. However, all researchers and local research collaborators who intend to participate in this study at NHS sites should seek approval from the R&D office for the relevant care organisation.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/H0205/14

Please quote this number on all correspondence

Yours sincerely

Dr Simon Bolam
Chair
Somerset Research Ethics Committee

Email: alison.courtney@tst.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Dr Eloise C J Carr, Bournemouth University
Royal London House, Christchurch Road
Bournemouth, Dorset
BH1 3LT

Mrs Sue Bulley
R&D Department
Yeovil District Hospital NHS Foundation Trust,
Yeovil, Somerset
BA21 4AT

Somerset Research Ethics Committee
Attendance at Committee meeting on 12 March 2008
Committee Members:

| Name | Profession | Present | Notes |
|----------------------|-----------------------------------|---------|-----------------------------|
| Mr Jon Beard | Chief Pharmacist | Yes | |
| Dr Jon Bell | Consultant Radiologist | Yes | |
| Dr Simon Bolam | Consultant in General Haematology | Yes | Chair of the Committee |
| Dr Lee Burton | GP | Yes | |
| Ms Jacq Clarkson | Statistician | Yes | |
| Dr Alan Cockett | Consultant Psychiatrist | Yes | |
| Dr Frank Green | Lay member | Yes | |
| Mr Alan Hopper | Lay member | Yes | Vice Chair of the Committee |
| Mrs Sally Moran | Lead Nurse Practice Development | Yes | |
| Mrs Rebecca Parkes | Lay member | No | |
| Dr Justin Pepperell | Consultant Physician | Yes | |
| Mrs Joan Ramsay | Associate Director of Nursing | Yes | |
| Revd Phil Regan | Lay member | Yes | |
| Mrs Sheila Rexworthy | Lay member | Yes | |
| Dr Debbie Stalker | Consultant Paediatrician | No | |

Also in attendance:

| Name | Position (or reason for attending) |
|---------------------|------------------------------------|
| Mrs Alison Courtney | REC Co-ordinator |

APPENDIX 2 : Participant information sheet phase 1

LREC number: 08/H0205/14

PARTICIPANT INFORMATION SHEET (post-ASPIRE study)

We would like to invite you to take part in a research study. Before you decide we would like you to read the following information in order for you to understand why the research is being done and what it will involve.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Take time to decide whether or not you wish to take part.

PART ONE

What is the purpose of the study?

The purpose of the study is to identify the impact of taking part in the ASPIRE programme.

Why have I been chosen?

You have been chosen as you have taken part in the ASPIRE programme.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do, you will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your role in any way.

What will happen to me if I take part?

You will be contacted for an appointment to take part in a taped individual interview.

Are there any risks associated with taking part?

The interview will involve answering questions about your views of the impact of attending the ASPIRE programme on participants (stroke survivors and carers).

What are the possible benefits of taking part?

You may benefit from someone taking a particular interest in and listening to you.

Will my taking part in the study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

PART TWO

What will the study involve?

The study will involve taking part in an individual, face-to-face, audio-taped interview lasting up to 2 hours. The interview will take place at a time and in a place convenient to you. This may for example be in your own home, in the researcher's office at the hospital or in the rehabilitation department where the ASPIRE programme was held.

A typed copy of the interview will be sent to you to check that we have correctly understood what you said in the interview.

What questions will I be asked in the interview?

You will be asked your views about the impact of the ASPIRE programme on participants (stroke survivors and carers).

What will happen if I don't want to carry on with the study?

You can let us know at any time if you do not wish to participate in the study and your data will be removed from our records.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential and will be stored in a database.

In the analysis of results, your data will be used anonymously.

Our procedures for handling, processing, storing and destroying data relating to your participation in the study are compliant with the Data Protection Act 1998.

What will happen to the results of the research study?

We will gather the results from individual participants and then we hope to publish our overall results in a scientific journal.

Who is organising and funding the research?

The researcher is Debbie Neal, Consultant Therapist at Yeovil District Hospital supported by her research supervisors at Bournemouth University. The research is being funded as part of a doctoral programme of study.

Who has reviewed the study?

This study has been reviewed by the researcher's supervisors at Bournemouth University and has been submitted for ethical approval for conduct in the NHS by the local Research Ethics Committee.

This information sheet is for you to keep. If you decide to take part you will be given a copy of the consent form which you sign when you agree to participate in the study.

Thank you very much for reading this information and considering taking part in the study. If there is anything you do not understand or if you have further questions please contact;

Debbie Neal. Telephone: 01935 384774. email: Deborah.neal@ydh.nhs.uk

Version 2

Date: 2/2/08

APPENDIX 3: Participant consent form phase 1

LREC number: 08/H0205/14

CONSENT FORM (post-ASPIRE study)

Participant identification number:

Name of Researcher: Debbie Neal

1 I confirm that I have read and understand the information sheet

dated 2nd February 2008 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2 I understand that my participation is voluntary and that I am free to

withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3 I agree to take part in the above study.

.....
.....
Name of participant Date Signature

.....
.....
Name of person taking consent Date Signature
(if different from researcher)

.....
.....
Researcher Date Signature

1 copy for participant, 1 for researcher.

Version 2
Date: 2/2/08

APPENDIX 4: Example transcript excerpt from S1

I: Yes. And do you remember about the ASPIRE programme?

S1: Yes. Very much so. Because if you come out of hospital and you, you're on your own, you're in home and you take to reading a little bit about what a stroke is, and what damage it's done and so on. But there's nothing to say here's how you recover.

I: Yes

S1: And I think the ASPIRE group helped me, give me confidence by saying things like you will do these things, you will get better. That was the reinforcing part of it, somebody being encouraging and saying you know...somebody....I mean your wife can be encouraging and say you things that....she doesn't really know. But you get somebody who is in the know and when they say you WILL recover, you tend to rely on that and trust them, and sure enough, you do.

I: And when you say 'somebody in the know', do you mean?

S1: Somebody with experience

I: Other people who have had stroke or do you mean?

S1: No, the physiotherapist and the nurses down at ASPIRE. They know about strokes and they can drive a person onto, onto later recovery. Like giving them exercises, giving them encouragement, which is what you need, encouragement. Because it's quite easy for me to be discouraged I suppose, that's for most stroke victims is....

I: So.....

S1: So it would be more easy for me just to sit down in the afternoon and watch television

I: Yes

S1: If I had a choice and rather than doing things, but like I say, my wife encourages me to do things because you can't

I: So what impact do you think the ASPIRE programme had on you?

S1: The impact it's had on me I think, it's given me the courage to carry on. It's given me the, how can you say, given me the....it makes you, it buoys you up.

I: Yes

S1: It buoys you up to say there is a future out there, you will get better and you will carry on and do the things...That's what the ASPIRE has done to me. Not just in the exercise machine, they were incidental, but the major part of it was maybe to meet other and see how they recover and you think, well if they can recover, I can recover. And the physiotherapist down there give you the relative exercises and giving you encouragement, and that's been important to me. That's what drove me on I think and that's what helped me to recover. That's my opinion anyway.

I: And what impact do you think the ASPIRE programme had on Julia?

S1: Oh she loved it. Because she, I think she could, well she liked it because of the social side of course, but she could also see that there was improvements in me. I don't know whether there would have been improvements anyway, it may be, but in the longer term. But she could see the, the improvements in myself. We used to go there..., even if, little things, like when you walked from the car park to the aspire group and you'd walk along to the aspire group and you'd meet people. One of the good things about the aspire group, I think as well was always the talks afterwards. Very enlightening. Put you in the picture about your lifestyle, where you had gone wrong, the tablets and so on and so forth. That could be very knowledgeable, that was very interesting.

I: so what would you change about the aspire group?

S1: I think as regards, I think what I'd change I think, not so much change I think, yes, maybe so, was to channel each individual needs. I mean we're all individuals, in some their hands are not right, and feet and speech and so on, and rather than put everybody on the treadmill, and everybody on the rowing machine, those that need it should be on those and those that have got hands they can't use, more, there must be more exercises to do with the hands.

I: yes.

S1: Rather than. I mean, you can go on the rowing machine until kingdom come but your hand is still not as it should be. That's what personally I wanted, was something to improve my hand.

I: There was a limited number of things to do with the hand.

S1: There was yes. I mean you could use the walking stick, picking things out of the tub, and there must be some other things that you can use. I don't know what they are, but there must be some things. Yes.

I: that's useful thank you.

APPENDIX 5: ASPIRE Clinician Information Sheet

ASPIRE

Acute Stroke, Self-management support, Secondary Prevention, Information, Rehabilitation, & Exercise Programme

What: A follow up programme for patients and their carers who have recently been diagnosed with Stroke or TIA that

- enables reinforcement of secondary prevention through interactive education sessions supported by information provision,
- provides individually tailored exercise and activity to enhance their physical fitness and complement their existing rehabilitation

Why: It is well recognised that vascular risk can be reduced through lifestyle changes such as reducing obesity, smoking cessation, dietary modification and increased levels of physical activity after stroke (Sacco et al, 2006). Recent data however indicates that patients' and carers' knowledge of stroke and how to prevent a further event is poor (National Audit Office, 2010). Although there is some evidence to suggest that self management strategies (Sit et al, 2007, Marsden et al, 2010) and physical fitness training (Saunders et al, 2016) can be used effectively in stroke, fitness levels after stroke are generally low and many stroke survivors lack the confidence to increase their levels of physical activity. The ASPIRE programme supports those after stroke to increase their physical activity levels, implement secondary prevention advice and provides peer and carer support (Neal, 2009).

Where: The weekly sessions are currently being held in the Rehabilitation Department at Yeovil District Hospital Foundation Trust.

When: Admission is via referral from a GP or the inpatient stroke team at YDH. It is held every Thursday for 1.5 hours for 12 weeks. The programme is a pilot with ongoing review and development.

How: On their first attendance patients are supported to identify their goals of attending and agree a plan for achieving those goals. In addition to attending the ASPIRE programme, this often includes a home exercise programme and signposting to other services.

Who: Any patient who has recently been given a diagnosis of Stroke / TIA who can attend the full 12 week programme and is medically fit and motivated to attend is eligible for referral. Attendance is for a maximum of 12 patients but numbers may vary depending on the level of disability and individualised needs. The clinic is run by Debbie Neal, Consultant Therapist for Rehabilitation and Caroline Smith, Consultant Nurse for Acute Stroke supported by other members of the multidisciplinary team. Please note we are unable to provide transport to this programme for those ineligible for ambulance transport though can advise on community transport options that may be available in the area.

ASPIRE

Acute Stroke, Self-management support, Secondary Prevention, Information, Rehabilitation, & Exercise Programme

What: A follow up group programme for people who have recently been diagnosed with Stroke or Transient Ischaemic Attack (TIA) that

- Helps you to understand how to avoid having another stroke.
- Includes exercise and activity to increase your physical fitness and complement any other rehabilitation you may be having.
- Gives you and those close to you chance to meet and talk to other people who have had a stroke / TIA and health professionals with expertise in stroke.

Why: Surveys have shown that people who have had a stroke / TIA may not know much about stroke and how to prevent having another one. Surveys have shown that it can be difficult to get the information you need.

Where: The weekly sessions are currently being held in the Rehabilitation Department at Yeovil District Hospital Foundation Trust.

When: Referral is usually from the inpatient stroke team or your GP. It is held every Thursday morning for 1.5 hours for 12 weeks. Your first appointment will be slightly longer to allow time for an individual session first. The programme is a pilot with ongoing review and development.

How: On your first attendance you will be supported to identify your goals of attending and agree a plan for achieving those goals. In addition to attending the ASPIRE programme, this often includes a home exercise programme and may involve signposting you to other services e.g. Proactive exercise scheme, physiotherapy, optician, counsellor, driving assessment. We can also measure your blood pressure and weight for you.

Who: Anyone who has recently been given a diagnosis of Stroke / TIA who can attend the full 12 week programme and is medically fit and keen to attend can be referred. Your husband or wife, close family member or friend is also welcome to join you for these sessions.

The clinic is run by Debbie Neal, Consultant Therapist for Rehabilitation and Caroline Smith, Consultant Nurse for Stroke, with visits from other people such as dieticians.

Please note we are unable to provide transport to this programme unless you meet the eligibility criteria for ambulance transport. We can advise on community transport options that may be available in your area.

APPENDIX 7: ASPIRE appointment letter

Yeovil District Hospital 
NHS Foundation Trust

Stroke rehabilitation office
Yeovil District Hospital
Higher Kingston
Yeovil
Somerset
BA21 4AT
Switchboard: 01935 475122
Direct line: 01935 384826

ASPIRE

Acute Stroke, Self-management support, Secondary Prevention, Information, Rehabilitation, & Exercise Programme

Dear

Re: ASPIRE Appointment

Following your stroke we have received a referral for you to attend the ASPIRE programme from the stroke team.

As discussed on the phone an appointment has been made for **Thurs 2013 at am**. This appointment will finish about . Future appointments for this programme if you choose to attend can either be from 10.30am to 12 noon OR 11.30am to 1pm (your choice). If you decide not to attend could you please inform the stroke rehabilitation team as soon as possible on 01935 384826 so we can reallocate your appointment.

If possible please bring with you a list of your current medications and also the enclosed questionnaires. If you have any difficulty in completing the questionnaires we will assist you to do so at your first appointment.

On arrival to the hospital please report to the Physiotherapy Outpatients Department which is located on Level 3 and inform the receptionist that you are booked into the ASPIRE clinic. **You are welcome to bring a family member or friend with you.**

If you have any questions before then or if you are unable to attend please contact Debbie Neal on 01935 384826.

Thank you,

Yours sincerely

Debbie Neal
Consultant therapist – rehabilitation

APPENDIX 8: Outcome tools used in Phase 2

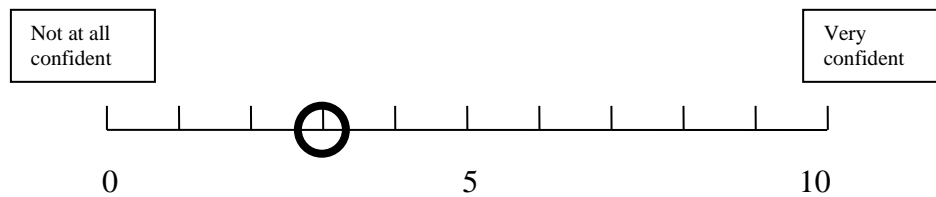
8a: The Stroke Self – Efficacy Questionnaire (Jones, 2008)

These questions are about your confidence that you can do some tasks that may have been difficult for you since your stroke.

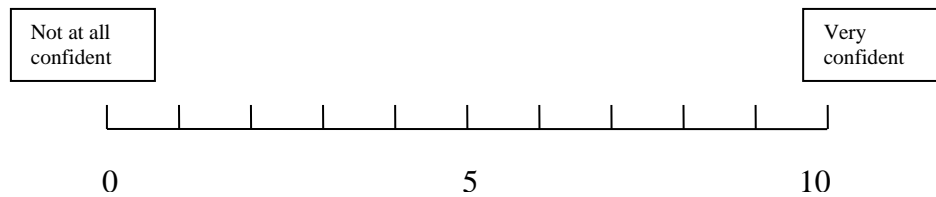
For each of the following tasks, please circle a point on the scale that shows how confident you are that you can do the tasks now in spite of your stroke.

Where 0 = *not at all confident* and 10 = *very confident*.

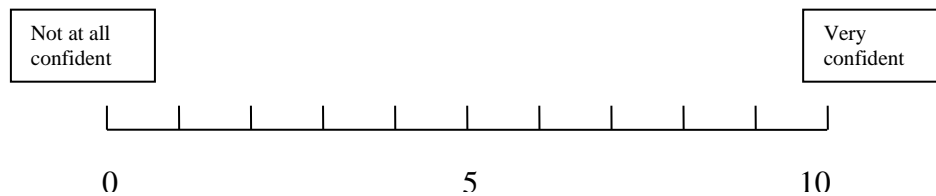
Example:



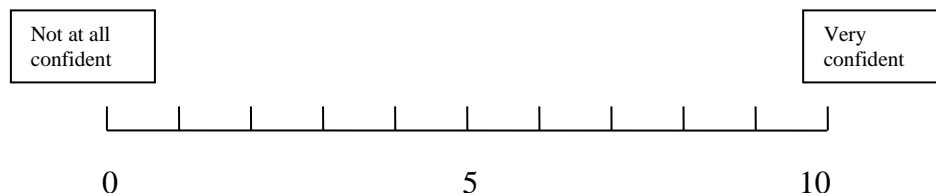
1. How confident are you that you can get yourself comfortable in bed every night?



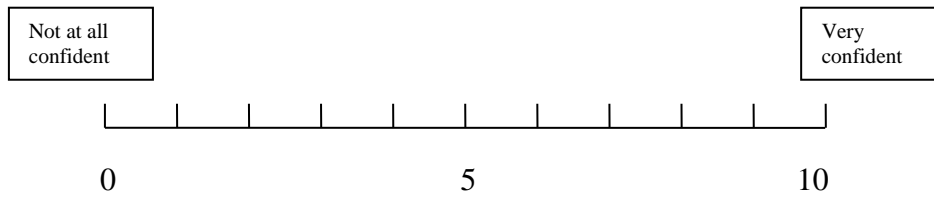
2. How confident are you that you can get yourself out of bed on your own even when you feel tired?



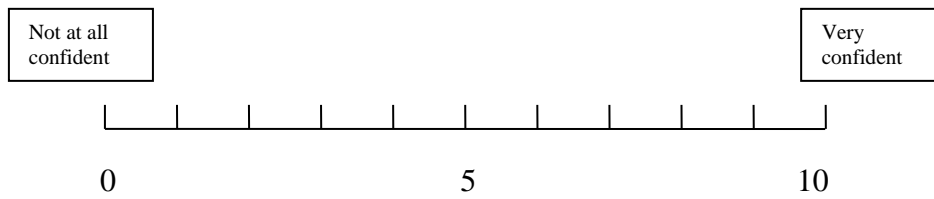
3. How confident are you that you can walk a few steps on your own on any surface inside your house?



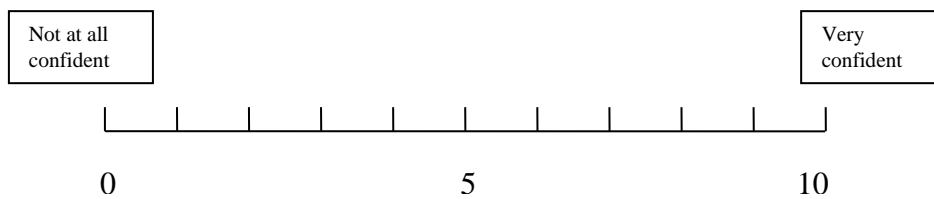
4. How confident are you that you can walk about your house to do most things you want?



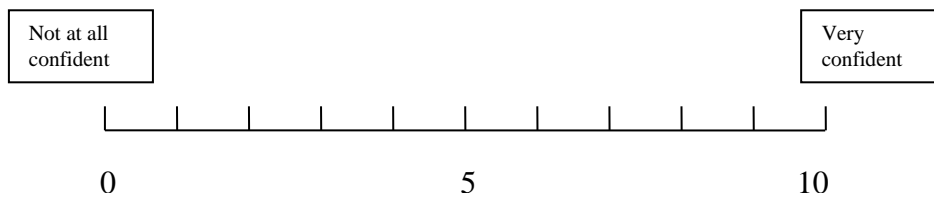
5. How confident are you that you can walk safely outside on your own on any surface?



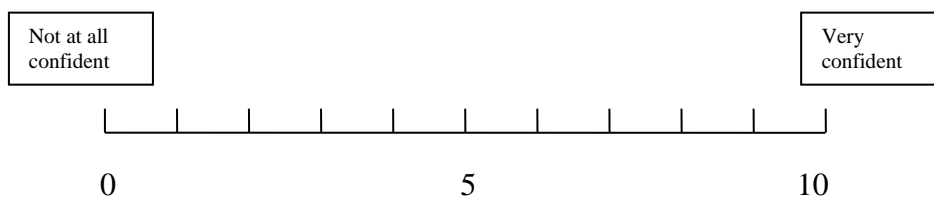
6. How confident are you that you can use both your hands for eating your food?



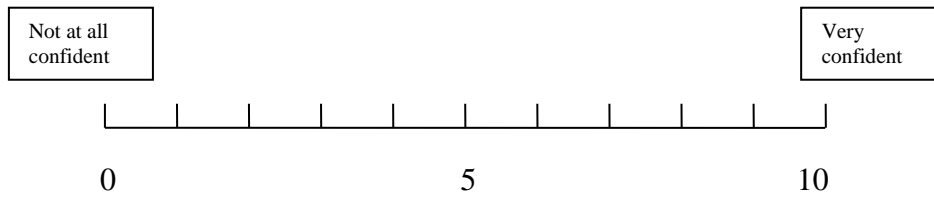
7. How confident are you that you can dress and undress yourself even when you feel tired?



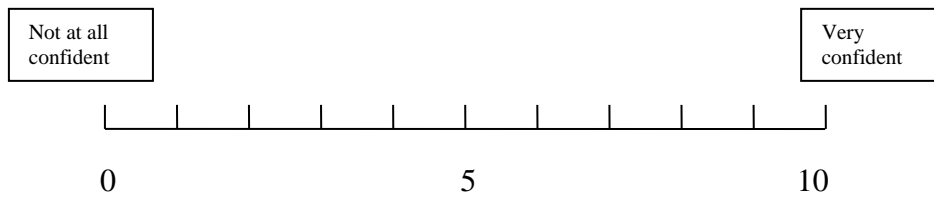
8. How confident are you that you can prepare a meal you would like for yourself?



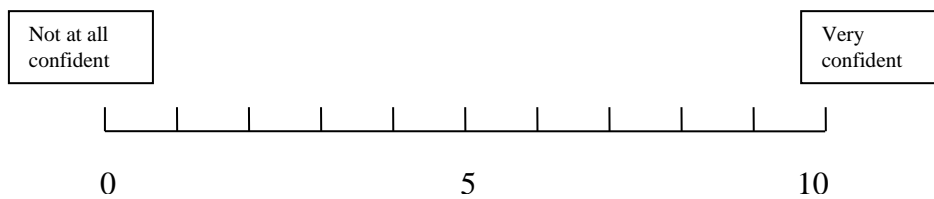
9. How confident are you that you can persevere to make progress from your stroke after discharge from therapy?



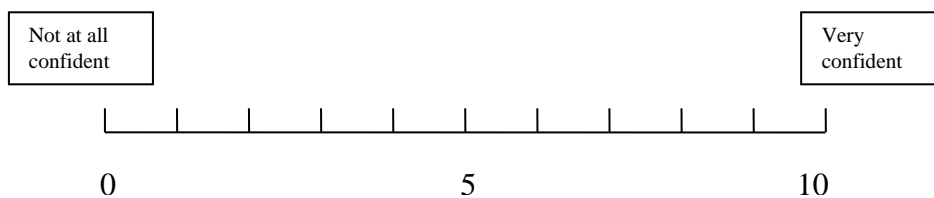
10. How confident are you that you can do your own exercise programme every day?



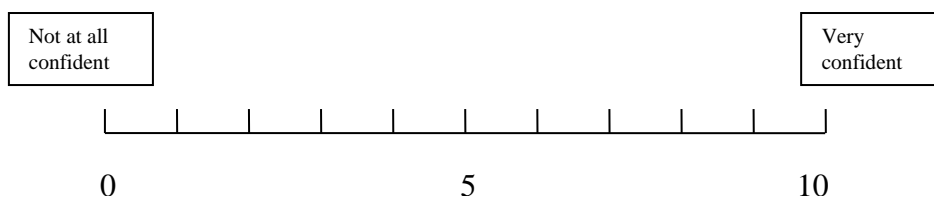
11. How confident are you that you can cope with the frustration of not being able to do some things because of your stroke?



12. How confident are you that you can continue to do most of the things you liked to do before your stroke?



13. How confident are you that you can keep getting faster at the tasks that have been slow since your stroke?



8b CABS-R

| Stroke Risk Questionnaire | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| It would be easy for me to exercise regularly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a lot to gain from exercising | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| It is likely that I will undertake regular exercise in the next 6 months | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am afraid to exercise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| It is likely that I will undertake regular exercise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Exercise will help me avoid stroke | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Most people who are important to me would want me to exercise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Exercising makes me feel better | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| It is likely that I will have a stroke if I don't exercise regularly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Generally speaking, I intend to undertake regular exercise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| It would be hard for me to exercise regularly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| The likelihood of my having a stroke is high if I don't exercise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I don't have time to exercise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Most people who are important to me would approve of me exercising | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Exercising interferes with my other activities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I enjoy exercising | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I feel too embarrassed to exercise | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I intend to undertake regular exercise in the next 6 months | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Exercising can be painful for me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My chances of having a stroke are high if I don't exercise regularly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please tick the box that applies

Excerpt from CABS-R (ka.sullivan@qut.edu.au)

8C STROKE KNOWLEDGE TEST (SKT) © Developed by Karen Sullivan, PhD & Natalie Dunton, 2001

1. The most common type of stroke occurs when
 - (a) The blood supply to the brain is blocked
 - (b) You are having a heart attack
 - (c) There is bleeding in the brain
 - (d) You've had too much sun
 - (e) I don't know

2. Which of the following will double your risk of stroke?
 - (a) If you are asthmatic
 - (b) If you are diabetic
 - (c) If you exercise too much
 - (d) All of the above
 - (e) I don't know

3. A type of irregular heartbeat known as Atrial Fibrillation (AF)
 - (a) Decreases the risk of stroke
 - (b) Doubles the risk of stroke
 - (c) Increases the risk of stroke by more than 5 times
 - (d) Is not a risk factor of stroke
 - (e) I don't know

4. Which age group is more at risk of stroke?
 - (a) 20-30
 - (b) 31-50
 - (c) 51-60
 - (d) 61+
 - (e) I don't know

5. The warning signs of Transient Ischaemic Attack (TIA) disappear
 - (a) Within 24 hours
 - (b) Within 48 hours
 - (c) After several days
 - (d) After several years
 - (e) I don't know

6. Which of the following is a warning sign of stroke?
 - (a) Sudden blurred vision
 - (b) Paralysis on one side of the body
 - (c) Severe headache
 - (d) All of the above
 - (e) I don't know

7. For someone who has had a stroke, the main purpose of rehabilitation is to
 - (a) Make sure they don't take drugs
 - (b) Keep them in hospital as long as possible
 - (c) Improve their level of daily functioning
 - (d) Keep their mind off it

- (e) I don't know
8. Taking aspirin assists in preventing stroke by
- (a) Stopping the formation of blood clots
 - (b) Getting rid of a headache
 - (c) Settling your stomach
 - (d) Relieving stress
 - (e) I don't know
9. You are at greater risk of stroke if
- (a) You are obese
 - (b) You exercise regularly
 - (c) You give up smoking
 - (d) All of the above
 - (e) I don't know
10. Once you have suffered a Transient Ischemic Attack (TIA)
- (a) You are less likely to have a major stroke
 - (b) You are more likely to have a major stroke
 - (c) You are less likely to have a heart attack
 - (d) You are more likely to have a heart attack
 - (e) I don't know
11. Surgery can sometimes help to prevent another stroke by
- (a) Giving a transfusion
 - (b) Cutting off the supply of blood to the brain
 - (c) Unblocking the arteries in the neck
 - (d) Removing the arteries
 - (e) I don't know
12. What method of treatment is available for people who have had a stroke?
- (a) Medication
 - (b) Rehabilitation
 - (c) An operation
 - (d) All of the above
 - (e) I don't know
13. The most important known risk factor for stroke is
- (a) Genetic
 - (b) Heart attack
 - (c) High blood pressure
 - (d) Old age
 - (e) I don't know
14. Approximately how many people in the UK are affected by stroke every year?
- (a) 1500
 - (b) 10 000
 - (c) 20 000
 - (d) 150 000
 - (e) I don't know

15. If you drink alcohol excessively you are

- (a) Less likely to have a stroke
- (b) Twice as likely to suffer stroke
- (c) Three times as likely to suffer stroke
- (d) Four times as likely to suffer stroke
- (e) I don't know

16. Which of the following is an example of a physical disability caused by stroke

- (a) The right arm is paralysed
- (b) There are problems with memory
- (c) Unable to speak properly
- (d) Having trouble doing things in the correct order
- (e) I don't know

15. To reduce the risk of stroke you need to

- (a) Eat well and exercise regularly
- (b) Ensure your blood pressure is not too high
- (c) Monitor your cholesterol levels
- (d) All of the above
- (e) I don't know

18. Smoking 20 cigarettes per day increases the risk of stroke by

- (a) 2 times
- (b) 4 times
- (c) 6 times
- (d) 8 times
- (e) I don't know

19. If someone has a stroke, when should you ring for an ambulance?

- (a) Only ring if the symptoms stay after 24 hours
- (b) Always ring for an ambulance straight away
- (c) Just see your doctor when you can
- (d) You don't need to ring an ambulance
- (e) I don't know

20. Rehabilitation can assist someone who has suffered

- (a) Loss of movement
- (b) Loss of speech or language
- (c) Loss of balance
- (d) All of the above
- (e) I don't know

8d HADS

ASPIRE

Acute Stroke, Self-management support, Secondary Prevention, Information, Rehabilitation, & Exercise Programme

This questionnaire helps us to know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important.

| | | |
|----------|---|------------------|
| A | I feel tense or 'wound up': Most of the time A lot of the time From time to time (occ.) Not at all | 3 2 1 0 |
| D | I still enjoy the things I used to enjoy: Definitely as much Not quite as much Only a little Hardly at all | 0 1 2 3 |
| A | I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all | 3 2 1 0 |
| D | I can laugh and see the funny side of things: As much as I always could Not quite so much now Definitely not so much now Not at all | 0 1 2 3 |
| A | Worrying thoughts go through my mind: A great deal of the time A lot of the time From time to time, but not often Only occasionally | 3 2 1 0 |
| D | I feel cheerful: Not at all Not often Sometimes Most of the time | 3 2 1 0 |
| A | I can sit at ease and feel relaxed: Definitely Usually Not often Not at all | 0 1 2 3 |
| D | I feel as if I am slowed down: Nearly all the time Very often Sometimes Not at all | 3 2 1 0 |
| A | I get a sort of frightened feeling like "butterflies" in the stomach: Not at all Occasionally Quite often Very often | 0 1 2 3 |
| D | I have lost interest in my appearance: Definitely I don't take as much care as I should I may not take quite as much care I take just as much care | 3 2 1 0 |
| A | I feel restless as I have to be on the move: Very much indeed Quite a lot Not very much Not at all | 3 2 1 0 |
| D | I look forward with enjoyment to things: As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all | 0 1 2 3 |
| A | I get sudden feelings of panic: Very often indeed Quite often Not very often Not at all | 3 2 1 0 |
| D | I can enjoy a good book or radio/TV program: Often Sometimes Not often Very seldom | 0 1 2 3 |

APPENDIX 9: Phase 2 Participant information sheet



**Bournemouth
University**

School of Health and Social Care

Debbie Neal, R601, Royal London House

Christchurch Rd:

Bournemouth: BH1 3LT.

dneal@bournemouth.ac.uk

01935 384774

PARTICIPANT INFORMATION SHEET (ASPIRE study)

We would like to invite you to take part in a research study. Before you decide we would like you to read the following information in order for you to understand why the research is being done and what it will involve.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Take time to decide whether or not you wish to take part.

PART ONE

What is the purpose of the study?

The purpose of the study is to test out what measurement tools can be used to measure the impact of attending the ASPIRE programme. These tools may include questionnaires or tests of your ability to walk, balance and use your arms.

Why have I been chosen?

You have been chosen as you have been referred to take part in the ASPIRE programme. The ASPIRE programme is a follow up group programme for people who have recently been diagnosed with Stroke.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do, you will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. You may still participate in the ASPIRE programme whether or not you choose to take part in the research study.

What will happen to me if I take part?

You will be asked to complete 1 or 2 short questionnaires at the beginning and again at the end of the ASPIRE programme. Where appropriate, postage paid envelopes will be provided for return of the questionnaires to allow you to have

sufficient time to complete the questionnaires undisturbed. On your first and last attendance at the ASPIRE programme we may also test out your ability to walk, balance and use your arms.

Are there any risks associated with taking part?

You may find it upsetting to complete the questionnaires or have your abilities measured as it might highlight the effects your stroke has had on you.

What are the possible benefits of taking part?

Previous participants have told us about the impact of attending the ASPIRE programme. By taking part in this study you will benefit from someone taking a particular interest in you and measuring your progress.

Will my taking part in the study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

PART TWO

What will the questionnaires be about?

The questionnaires will be about how life is for you since your stroke. They may include questions about your mood, quality of life and confidence in managing your health.

What will happen if I don't want to carry on with the study?

You can let us know at any time if you do not wish to participate in the study and your data will be removed from our records and will not be used.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential and will be stored in a database for 7 years before being securely destroyed.

The researchers carrying out this study will have access to your electronic and paper medical records.

In the analysis of results, your data will be used anonymously.

Our procedures for handling, processing, storing and destroying data relating to your participation in the study are compliant with the Data Protection Act 1998.

With your consent, we will inform your GP of your participation in our study.

However, we will not share with them the data about you that we obtain from your participation in the research.

What will happen to the results of the research study?

We will gather the results from individual participants and then we hope to publish our overall results in a scientific journal.

Who is organising and funding the research?

The researcher is Debbie Neal, Consultant Therapist at Yeovil District Hospital supported by her research supervisors at Bournemouth University. The research is being funded as part of a doctoral programme of study.

Who has reviewed the study?

This study has been reviewed by the researcher's supervisors at Bournemouth University and has been submitted for ethical approval for conduct in the NHS by the local Somerset Research Ethics Committee.

This information sheet is for you to keep.

If you decide to take part you will be given a copy of the consent form which you sign when you agree to participate in the study.

Thank you very much for reading this information and considering taking part in the study.

If there is anything you do not understand or if you have further questions please contact;

Debbie Neal. Telephone: 01935 384774.

email: dneal@bournemouth.ac.uk

APPENDIX 11

LEAGUE OF FRIENDS REQUEST FORM

Requested By: Debbie Neal Consultant Therapist-Rehabilitation

Dept/Ward: Rehabilitation Tel Ext:

Date: 18th November

Description of Equipment :

The balance trainer is a piece of equipment that assists someone with limited or severely limited ability to stand onto their feet and supports them securely. It can also be used for balance training in standing.

- Balance function with adjustable resistance
- Releasing and blocking of the balance function with the release lever on the table (6° and 12° of freedom)
- Stable frame with four lockable castors
- Metal foot plate with heel cups and foot fixings
- Wooden table with cushioned cut-out for the body
- Height adjustment of table with help of gas spring support
- Hand rail height right/left adjustable
- Biofeedback provided by software
- Length 118cm, width 78cm, Height 95 – 125cm
- Weight 71.6kg
- CE, ISO 9001:2000, DIN-ISO 13485, EMV

A 2 hour training session is provided by the company in the use of the balance trainer and software. The company will provide training competency checklist.

Cost of Item: £14,674
(Excluding VAT)

Total: £ 14,674

Has this request been approved by the Medical Devices Committee?: ✓
YES NO

Medical Devices Committee have approved request for **two** medical devices.

Reason for Request

This piece of equipment enhances recovery and improves the patient experience by enabling standing at an early stage after illness or injury with minimal manual handling.

It has been suggested for use with those with neurological conditions such as paraplegia, in those with dementia and in the elderly at risk of falling.

During the 4 weeks we trialled the equipment earlier this year it was used to support the recovery of a wider range of patients including:

- A tall young man who had sustained a brain injury - it was used whilst he was still being ventilated on the intensive care unit and also after transfer to a side room on a ward.
- An older lady recovering from major surgery who was severely debilitated.

- An elderly gentleman recovering from a stroke who was able to mobilise with a frame but was at risk of falls due to poor balance.

Clinical benefits

- Allows balance training and standing practice
- Increase stability in hips, pelvis and upper body
- Reduces tone where spasms or spasticity is a problem and helps prevent contractures in the lower limb.
- Enables improvements in breathing and circulation
- Positive benefits of weight bearing including on urinary drainage, the digestive tract and bone density.

Advantages of this particular model

- Although there are many static standing frames on the market this is the only one that also allows balance training.
- Due to the small size & manoeuvrability of equipment it can be used by the bedside including if a patient is confined to a side room or has insufficient exercise tolerance to be transported to a rehabilitation area.
- Due to the use of pelvis strap and hip, foot and knee supports rather than overhead supports it can be used with very tall patients.
- Multi-adjustable in terms of height, hip width, position of knee and foot supports, 3 different pelvic belts so can be used with people with a range of different shapes and sizes. Height range 150 – 200 cm, 4’ 11” to 6’ 7”, Maximum weight; 140kg i.e. 22 stone
- Can be used to stand from a bed, wheelchair or chair
- Comes with software on a CD ROM of balance measurement tools and games to aid motivation and provide a fun stimulus to rehabilitation.
- In suitable patients not needing the foot straps it can be used in combination with the Wii Balance Board and Wii fit package.

Health and Safety:

Come with a 3 year guarantee. CE marked
Needs annual LOLER check in-house.

Cleaning / infection control

Can be cleaned with alcohol wipes.

Not recommended for use with patients with MRSA or C. Diff.